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# Services, Systems and Policies Shaping Community Mobility for People with Mobility Impairments: A Case Study from Northern Iceland

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Graduate Program in Health and Rehabilitation Sciences  
A thesis submitted in partial fulfillment of the requirements for the degree in Doctor of Philosophy  
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## Abstract

Community mobility, or the act of moving around within the community, can be thought of as an occupation, but also as a means to occupation, because it is essential for people to have opportunities to participate in society. People with mobility impairments do not have the same opportunities as other people to move around because of multiple challenges in the environment. This research aimed to enhance understanding of how services, systems and policies shape community mobility of people with mobility impairments in the town of Akureyri in northern Iceland. This dissertation further raises awareness about human rights, occupational rights and occupational justice issues regarding the relationship between these infrastructure factors and community mobility for this group.

Case study methodology was used, which includes using multiple methods for data collection. Two focus group interviews were conducted with people with mobility impairments, and one with service providers working within the disability sector. Based on findings from these focus groups, two policy areas were identified that are essential to support community mobility, that is transportation services and accessibility. Those policy areas were then explored further with a review of publicly available policy documents.

The overall findings of this case study highlight key areas that could improve community mobility of people with mobility impairments if taken into consideration in all policy development in Iceland. Those areas are regarding (1) Users' involvement in policy development; (2) Clarity and consistency of policy texts; (3) Monitoring of the system as a whole; and (4) Occupational right and justice values in policies.

The findings indicate that current policies are not sufficiently congruent with the United Nations' Convention on the Rights of Persons with Disabilities, and people with mobility impairments are subject to occupational injustices and violation of occupational rights, which originates at the system level. This work points to the need to reconsider the way policies are developed and has implications not only for people with mobility impairments, but also policy makers, service providers, and researchers in the field.

## Keywords

Case study; Community mobility; Services, systems and policies; Mobility impairment; Occupational justice; Occupational rights; Human rights

## Co-Authorship Statement

I, Sigrún Kristín Jónasdóttir, acknowledge that this dissertation includes three manuscripts (chapters 2, 3 and 5) that evolved as a result of collaborative endeavors. In all those manuscripts, the primary intellectual contributions were made by me (the first author) who: researched the methodology, designed the research, developed the ethics application, conducted literature reviews, established relationships with participants, undertook data collection, coded the data, led the data analysis and interpretation, and led the writing of the manuscripts.

The contribution of the co-author Dr. Jan Polgar (in all three manuscripts), was primarily through supervision of the research, theoretical and methodological guidance, reflexive dialogue and intellectual and editorial support in crafting the work for publication.

The contribution of the co-author, Dr. Snæfríður Þóra Egilson (in chapter 5) was primarily through theoretical and methodological guidance, review of data analysis, reflexive dialogue, and editorial support.

The contribution of co-authors, Dr. Carri Hand and Dr. Laura Misener (in chapter 3) were primarily through theoretical and methodological guidance, and reflexive dialogue.

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## Chapter 1

### 1 Introduction to the study

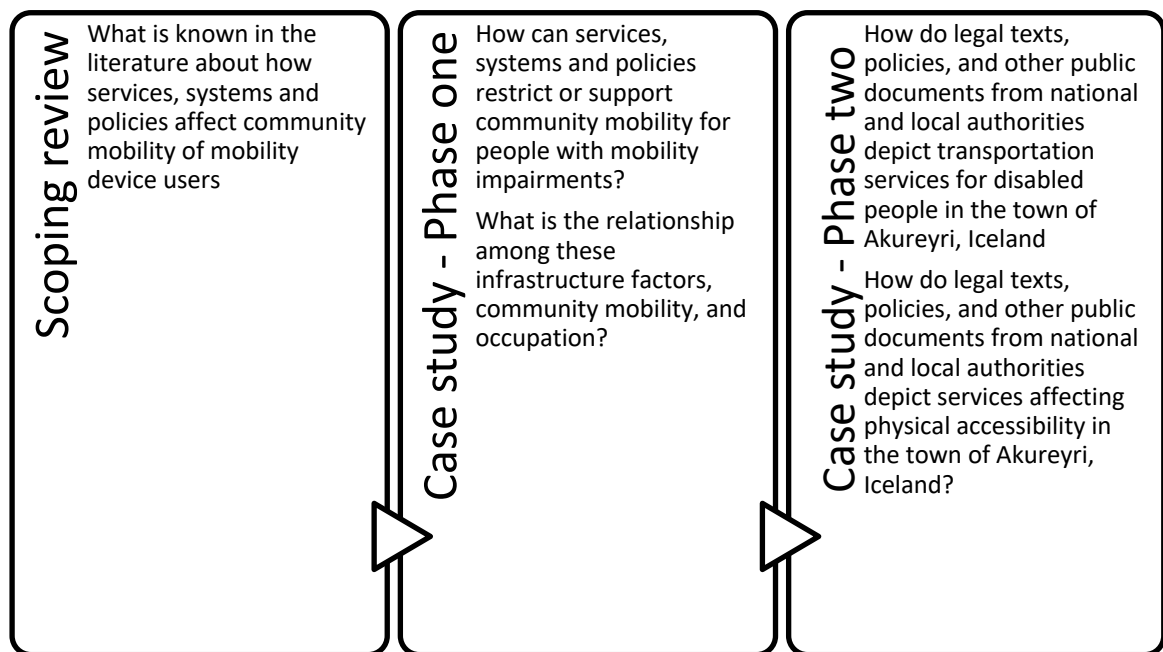
The United Nations' Convention on the Rights of Persons with Disabilities (CRPD), which aims attention on human rights of disabled people, was signed by the Icelandic government in 2007, and finally ratified in 2016 (Ministry of Justice, n.d.; United Nations, 2006). The signing of that convention pushed a gradual paradigm shift around policies and services for disabled people in Iceland, turning the focus more towards the contextual factors shaping their opportunities, rather than on their impairments as hindrances to participation. The Icelandic authorities have been working towards changing their legislations according to the CRPD, and one of the aspects that authorities need to consider is provision of resources, so people can move around their communities according to their own choice and time preferences (United Nations, 2006). That aspect is the topic of this dissertation.

More specifically, the objective of this dissertation was to enhance understanding of services, systems and policies that shape community mobility of people with mobility impairments in certain geographical location in northern Iceland. A case study methodology was used as it fits well to gain understanding of complex social and political phenomenon in its real-life context (Yin, 2014). To be more specific, this topic



was explored from the perspectives of people with mobility impairments in northern Iceland and service providers in the same area through focus group interviews, as well as through review of publicly available policy documents about service areas identified by the focus groups. The research questions started broad but got more precise with every stage of the research process. The specific research questions addressed on different stages of the research process can be seen in figure 1.

**Figure 1: Research questions on different stages of the research process**



The data analysis and interpretations were guided by human rights (United Nations, 2006), occupational rights (Hammell, 2008), and occupational justice (Wilcock, 2006) perspectives. This dissertation gives valuable information that can assist in developing strategies to guide development and practice within the policy sector in Iceland to improve the opportunities people with mobility impairments have to move around in their communities and fully participate in society on an equal basis as others.

Below in this chapter, I will reflect on what motivated me to conduct this research. Next, I clarify key terms that are used throughout this dissertation. Following, I explain briefly the theoretical perspectives that guide the study, and lastly, the organization of the dissertation is presented.

## 1.1 Reflections on what motivated this study

I have always been fascinated about how the environment (in a broad sense) shapes what people can and cannot do. I remember wondering as a kid about how the environment could be adjusted to make it easier to do things, for example when working in the kitchen, or when helping my parents tending to the animals at the farm where I grew up.

As a teenager, I visited my grandma where she worked as a chef in a summer camp for disabled children. That was my first experience being around people who use wheelchairs and other mobility devices. During those visits, I recall questioning how the children

were able to go to the second floor, as there was no elevator in the public-school building where the camp took place. Not only were there stairs to go to the second floor, but there were also steps to enter the building, and to access the lunchroom which limited their abilities to move around the building by themselves.

As a novice occupational therapy student, I remember when our teacher asked us to go downtown and try to move around the “pedestrian street”, which is the main shopping area, using wheelchairs. Even though not a realistic situation, since we were fully able to walk, and thus could stand up any time we ran into problems, it still gave us ideas about the extensive accessibility issues people face every day when using mobility devices.

During my final year as an occupational therapy student, I conducted a small-scale study with my co-students regarding how people with spinal cord injury experienced the environment and what factors hindered their participation in society. Some of the main factors they identified were issues regarding accessibility, as well as systemic issues related to programs and services (Kristjánsdóttir, Benediktsdóttir, & Jónasdóttir, 2008).

As an enthusiastic newly graduated occupational therapist, I experienced that I had often very limited abilities to help my clients when it came to moving around in their communities. Sure, I had the abilities to apply for assistive devices with them, I could guide them on how to use those devices or help them make adaptation to make their

homes more accessible. But when it came to issues of moving around within their communities, I felt there was often little I could do. I started thinking about how those issues with going between places come about and how they might be fixed. With my previous focus being more on simply the physical environment, I started to realize that there were other factors that were crucial in shaping the physical environment. Later, I labeled those factors as services, systems and policies.

Even though I remember being interested in community mobility for a long time, I do not have the experience of being a mobility device user yet. However, I have worked closely with disabled people in the community, both in a rehabilitation center and with disabled people in their homes, where I frequently witnessed their daily struggles with mobility hindrances. For example, we had very limited resources to clear the parking lot of snow in a home for disabled people which was run by the local authorities. This caused some of the residents not being able to go from the house into a vehicle to commute to work. Another example was when the residents only had access to a vehicle (which rotated between different homes) one weekend each month. This resulted in residents with very different values and needs sharing a vehicle and going together to a predetermined destination. Even though I tried to advocate for them to have those hindrances removed, I was not successful. As an employee of the system, I encountered diverse policies and structural issues that affected the services we were providing.

During that same period of time, I was becoming aware of the CRPD and its importance for the human rights of disabled people. I realised how important this convention is for disabled people to have access to the same opportunities as any other people, and how those rights were frequently not being respected. This made me realize how complex the system is and sparked my interest in exploring it further. These experiences and thoughts, in addition to a gradual paradigm shift in society based on the CRPD, kindled my interest to conduct the case study presented in this dissertation.

## 1.2 Clarification of key terms

In this section, key terms that are used in this dissertation are clarified. These terms are: occupation; community mobility, mobility impairment; disability; services, systems and policies; transportation services; and accessibility.

### 1.2.1 Occupation

No consensus has been reached on a definition of the term occupation. Most simply defined, occupation is doing. However, life is complex and so is occupation. It has been defined as “various everyday activities people do... to occupy time and bring meaning and purpose to life... [including] things people need to, want to and are expected to do” (International Society of Occupational Science, n.d., p.1). Similarly, Wilcock and

Hocking (2015) define occupation as “all things that people need, want or have to do across the sleep-wake continuum, individually and collectively” (p.xi).

A fundamental aspect of the complexity of occupation is that it is about human beings doing something in context. Highlighting this connection, Dickie, Cutchin & Humphry (2006) describe occupation as “an important mode through which human beings, as organisms-in-environment-as-a-whole, function in their complex totality” (p. 83). It can further be seen in common occupational science and therapy models that human occupation cannot be separated from the context in which it takes place ( Dickie, et al., 2006; Kielhofner, 2008; Law, Cooper, Strong, & Stewart, 1996; Townsend & Polatajko, 2007; Wilcock & Hocking, 2015).

### 1.2.2 Community mobility

Community mobility refers to when people can move around within their communities “in accord with their needs and preferences” (Di Stefano, Stuckey and Lovell, 2012, p.98), using different means of transportation, such as driving, walking, riding a bus, biking etc. (The American Occupational Therapy Association, 2014). Community mobility is highly important for most people because it is not only an occupation (The American Occupational Therapy Association, 2014), but also a means to many other occupations people want or need to do to engage in their communities. Community

mobility is important for people to be independent and have opportunities to participate in society (Di Stefano et al, 2012).

### 1.2.3 Mobility impairment

The definition of mobility impairment used in this dissertation is based on the International Classification of Functioning, Disability and Health (ICF). Impairment is when an individual has some deviation from typical body function or structure. Impairments can vary regarding duration, for example they can be temporary or permanent, and they can also change with time, such as be progressive, regressive or intermittent (World Health Organization, 2001).

According to the ICF (World Health Organization, 2001) mobility refers to when an individual moves and changes body position or location. Mobility impairment is thus when a persons' mobility is limited due to an impairment.

All people who use mobility devices, such as wheelchairs, powered wheelchairs, walkers, canes etc. have mobility impairments. The focus of this study is on this particular population. Thus, when the term mobility impairment is used in this dissertation it refers to people with mobility impairments who use mobility devices on a daily basis. Still, it should be acknowledged that not all people with mobility impairments use mobility devices.

#### 1.2.4 Disability

The terms disability and disabled people are used throughout this dissertation. Disability can be understood from various perspectives. First, the most common understanding is based on a biological model, which does not address environmental factors but focuses on how to fix individuals. Second, there is a social model, which considers disability to be caused by the environment. And lastly, there is more relational understanding of disability which considers disability to be an interaction between individuals and surrounding context (Shakespeare, 2014; Tøssebro, 2004; World Health Organization, 2001). When I talk about disability, I am referring to the relational perspective of disability as defined in the United Nations' Convention on the Rights of Persons with Disabilities (CRPD). According to the CRPD “disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others” (United Nations, 2006, p.1). Even though the CRPD talks about *persons with disabilities*, I use the term *disabled people* (except when citing others) as is often used within disability studies to emphasise how people with impairments are disabled by the context they are in, such as by socio-political factors (Shakespeare, 2015; Stone, 2012).



### 1.2.5 Services, systems and policies

The definition I use of services, systems and policies does also originate from the ICF. Services, systems and policies are one of the domains of environmental factors that influence peoples' lives, as they can either hinder or facilitate their involvement in life situations (World Health Organization, 2001). The ICF definitions of these factors are the following:

Services

*“provide benefits, structured programmes and operations, in various sectors of society, designed to meet the needs of individuals. (Included in services are the people who provide them.) Services may be public, private or voluntary, and may be established at a local, community, regional, state, provincial, national or international level by individuals, associations, organizations, agencies or governments. The goods provided by these services may be general or adapted and specially designed”* (World Health Organization, 2001, p.192).

Systems are

*“administrative control and organizational mechanisms, and are established by governments at the local, regional, national, and international levels, or by other*

*recognized authorities. These systems are designed to organize, control and monitor services that provide benefits, structured programmes and operations in various sectors of society” (World Health Organization, 2001, p.192).*

And policies are

*“constituted by rules, regulations, conventions and standards established by governments at the local, regional, national, and international levels, or by other recognized authorities. Policies govern and regulate the systems that organize, control and monitor services, structured programmes and operations in various sectors of society” (World Health Organization, 2001, p.192).*

#### 1.2.5.1 Transportation services

There are two types of transportation services that are referred to in this dissertation. First, there is *public transportation* which in this case are fixed route buses – or a scheduled means of passenger transportation, and second *accessible transit services* specifically offered to disabled people. However, the use of the latter term developed throughout the research process. When writing up the manuscript presented in chapter five, I used the term transportation service, when referring to the accessible transit service. The reason for this is that *transportation service* is a direct translation of the Icelandic word used for the service. It was not until I was writing up chapter six that I

realised that it would be better to use transit services for this particular service, as it got confusing to use the terms transportation service and public transportation repeatedly. However, since chapter five had already been published, it does not reflect the evolution of the term used, and thus the term transportation service is still used in chapter five.

### 1.2.5.2 Accessibility

Even though the term accessibility is commonly used in daily life, there is no general agreement on how to define it (Iwarson & Ståhl, 2003). According to English Oxford dictionary (n.d.), accessibility simply means “the quality of being able to be reached or entered” (def.1).

Lid & Solvang (2016) understand accessibility to be “equal opportunity to make use of goods and benefits and to participate in ordinary, common life according to one’s preferences” (p.183). This definition brings in the importance of people having access to participate in society as they choose to do.

Accessibility can also be thought of as a human right, and as described in the CRPD it means “access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas“ (United Nations, 2006, p.9).

As the focus of this dissertation is on people with mobility impairments, the focal point regarding accessibility is on the physical aspect of it. Borrowing from ideas presented in the above definitions, a space is considered accessible if it is free of disabling barriers that hinders people to reach, enter and move around that space, according to their preferences, and on an equal basis with others.

### **1.3 Theoretical perspectives guiding this study**

This section introduces the theoretical perspectives that guided my analysis and interpretation of findings in this study. The theoretical perspectives that guide this study are human rights, occupational rights, and occupational justice perspectives.

#### **1.3.1 Human rights, occupational rights and occupational justice**

The United Nations state that “human rights are rights inherent to all human beings, whatever our... status. We are all equally entitled to our human rights without discrimination” (United Nations, n.d., para 1). The United Nations’ Universal Declaration of Human Rights presents the fundamental human rights we are all entitled to (United Nations, 1948). A more recent human right instrument is the Convention on the Rights of Persons with Disabilities (CRPD), which identifies both the right of disabled people, but also the obligations the society has to promote, protect and ensure those rights (United Nations, 2006).

There are two concepts derived from an occupational perspective that directly relate to human rights. Those concepts are *occupational rights* and *occupational justice*. The term occupational justice has been used in the literature since the 1990s, but it has been criticized for having little conceptual clarity (Durocher, Gibson & Rappolt, 2014). Due to that, Hammell (2017) suggests that we should focus on occupational rights. However, I see these concepts as interlinked and will explain my understanding below.

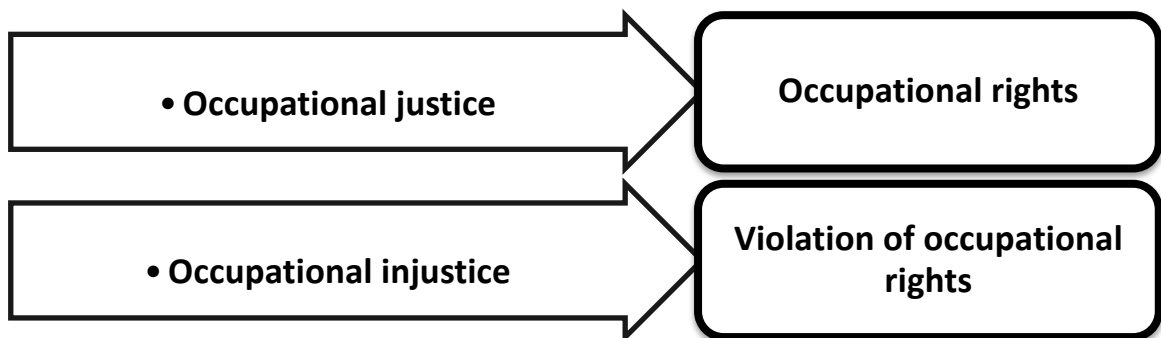
*Occupational rights* are about *doing*, or having opportunities to act (Hammell & Iwama, 2012). Hammell (2008) defined occupational right as “the right of all people to engage in meaningful occupations that contribute positively to their own well-being and the well-being of their communities” (p. 62). As identified by Wilcock and Hocking (2015), sixteen articles of the Universal Declaration of Human Rights directly address occupation: work (article 23), education (article 26), leisure (article 24) among others. Additionally, the World Federation of Occupational Therapists has asserted this idea of rights for occupation in a position statement on human rights, highlighting the right of all people to engage in a range of occupations and be supported to do so (Wilcock & Hocking, 2015; World Federation of Occupational Therapists, 2006). This right can also be called occupational right.

*Occupational justice* is about *having* resources, or about equitable distribution of resources in society to support occupation (Hammell & Iwama, 2012). Wilcock (2006)

defines occupational justice as “the promotion of social and economic change to increase individual, community, and political awareness, resources and equitable opportunities for diverse occupational opportunities that enable people to meet their potential and experience well-being” (p. 343).

Based on that, we can think of occupational rights to be the desired outcome for people, while occupational justice is the process to reach that outcome (see figure 2). For people to experience their occupational rights fulfilled, there is a need for occupational justice. This is especially important when people need some kind of support or adjustment in society to be able to take part in those occupations. Occupational injustices are when people are excluded or deprived of occupations that are meaningful to them by lack of resources, which results in a violation of people’s occupational rights (Hammell, 2017).

**Figure 2: The concepts of occupational justice and rights**



Occupational justice is a human right issue which is created by the broader social context in which we live (Wilcock and Hocking, 2015). Thus, to change occupational injustice into justice, something has to change in society. Hammell (2017) refers to the capabilities approach, suggesting the need to consider: “What are people actually able to do and to be? What real opportunities are available to them?” (Nussbaum, 2011, p. x). According to Wilcock and Hocking (2015) such injustices “can be confronted by empowering individuals, communities, and whole countries to improve their material, psychosocial, and political circumstances” (p.392). However, in order to confront occupational injustices, it is essential to know about them and raise awareness about them. To address those issues, we need to target policy making and urban planning, and change overall policies, instead of targeting single incidents (Hammell, 2017).

## 1.4 Plan of presentation

This dissertation is presented in an integrated article format and consists of seven chapters. Because three of those chapters (chapters 2,3, and 5) have already been published as individual manuscripts, there are repetitions between some of the chapters in this dissertation. This first chapter briefly set the stage for the research presented in the dissertation, by explaining my interest in the research topic, as well as clarifying and situating the main concepts that are employed through the dissertation. Additionally, the theoretical perspective that guided this research process is explained.

Chapter two serves as the literature review for this dissertation and consists of a scoping review which summarizes the knowledge in the literature on barriers and facilitators to community mobility, constructed by services, systems and policies. Gaps in the literature were identified, which set the stage for the study presented in this dissertation.

Chapter three introduces case study methodology and its relation to the study of occupation. The first part of the chapter gives an overview of what case study methodology is. The second part explores how case study methodology has been used for the study of occupation and gives recommendations regarding essential features of case study methodology in order to advance the use of it to study occupation.

Chapter four presents the way case study methodology (as described in chapter three) was used for this particular study presented in this dissertation. Aspects that are addressed in this chapter are the following: paradigmatic stance of the researcher, the research questions; definition of the case and its boundaries; study site selection, context of the case, data collection and analysis methods; and quality considerations.

Chapter five presents the first phase of the case study which included focus group interviews with people with mobility impairments in northern Iceland, and service providers in the disability field in the same location. The objective was to explore how services, systems and policies can restrict or support community mobility for people with



mobility impairments in that area. Additionally, the relationship between those infrastructure factors, community mobility and occupation were explored using an occupational lens.

Chapter six presents the second phase of the case study, which consisted of analysis of publicly available policy documents. The objective of this phase was to gain better understanding of the services, systems and policies around specific service areas identified in chapter five. Concerns that are common between those service areas are presented and discussed.

Chapter seven presents a short summary of each of the research phases of the case study and synthesis of common aspects identified in both phases. Based on those common aspects, suggestions are made for policy development in Iceland to advance the opportunities for community mobility of people with mobility impairments. Implications for occupational science, service users, policy makers, as well as service providers are presented. This chapter also reflects on the limitations of the study as well as directions for future research.

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## Chapter 2

### 2 Scoping review: services, systems and policies affecting mobility device users' community mobility<sup>1</sup>

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) emphasizes that all people have the right to full participation in society, and recognizes discrimination based on disability as a human rights issue (United Nations, 2006). Most countries in the world have signed the convention and the majority of them have ratified it (United Nations Enable, n.d.). According to Article 4 in the CRPD “state parties undertake to ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability” (United Nations, 2006, p. 5). This assertion means that the state parties are obligated to ensure that people who have some kind of impairment and are disabled by sociopolitical factors have equal opportunities for inclusion and participation in the society. For instance, the state parties are obligated to ensure that individuals with

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<sup>1</sup> A version of this chapter has been published: Jónasdóttir, S. K., & Polgar, J. (2018). Scoping review: Services, systems and policies affecting mobility device users' community mobility. *Canadian Journal of Occupational Therapy, 85*(2), 106–116. doi:10.1177/0008417417733273

mobility impairments have the same opportunities as others to move between places in the community to participate in common occupations such as work, school and social life (United Nations, 2006). In this paper, we use the term *disabled people* deliberately (except in quotations from others) to be consistent with the practice in disability studies that acknowledges the contextual elements as a primary source of disability (Shakespeare, 2015).

Carrying out common everyday tasks, such as attending work or school, running errands, visiting friends and family, and participating in social events, usually requires people to move around within their communities. Therefore, the opportunity to go from one place to another in the community is important for full participation in society. *Community mobility* refers to when people move between places within the community “in accord with their needs and preferences” (Di Stefano, Stuckey & Lovell, 2012 p.98) using various transportation modes (American Occupational Therapy Association, 2014). Community mobility for persons who have mobility impairments and use wheelchairs, walkers or other mobility devices (MD users) can be challenging, possibly restricting participation in activities that other people take for granted (World Health Organization, 2011).

According to the International Classification of Functioning, Disability and Health (ICF), services, systems and policies are one of the categories of environmental factors that can



either hinder or facilitate participation and performance of activities, such as mobility (World Health Organization, 2001). The ICF defines *services*, *systems* and *policies* as the following: Services “provide benefits, structured programmes and operations, in various sectors of society, designed to meet the needs of individuals” (World Health Organization, 2001, p. 192). Systems “are administrative control and organizational mechanisms, and are established by governments at the local, regional, national, and international levels, or by other recognized authorities” (World Health Organization, 2001, p. 192). Policies are “constituted by rules, regulations, conventions and standards established by governments.... [and they] govern and regulate the systems that organize, control and monitor services, structured programmes and operations in various sectors of society” (World Health Organization, 2001, p. 192). Examples of these environmental factors include a personal assistant (service), whose service is organized and funded by local authorities (system), in accordance with national legislation or international treaties (policies).

Services, systems and policies can influence people’s lives in multiple ways and are critical as they can have considerable impact on other environmental factors as well. Authorities, or the people who have administrative powers in the community, can have an impact on accessibility to the built and natural environment with the design, conditions and resources they support or provide. For example, policies and actions regarding quality and frequency of snow removal services will affect physical accessibility on the

streets. The state parties that have acceded to the CRPD have the obligation to ensure that their services, systems and policies do not disable people, such as those with mobility impairments, but rather support and facilitate their inclusion in society. However, for authorities to implement measures to fulfill the obligations of the CRPD, they will need appropriate information to build on, such as how and if services, systems and policies are affecting the subject matters of the convention, in this instance, community mobility.

## 2.1 Study purpose

The first step to approach this need for more information is to summarize existing knowledge in the literature and identify gaps related to services, systems and policy factors affecting community mobility of MD users. The aim of this scoping review is to summarize the literature on community mobility barriers and facilitators created for this group by services, systems and policies as defined by the ICF and identify areas that need to be researched further on this subject.

## 2.2 Method

Arksey and O'Malley's (2005) approach for scoping studies was used for the review and summary of services, systems and policy factors affecting community mobility. The approach describes the following five stages when conducting a scoping review (1) identifying the research question, (2) identifying relevant studies, (3) selecting

studies, (4) charting the data, and (5) collating, summarizing and reporting the results (Arksey & O'Malley, 2005).

### 2.2.1 Identifying the research question

The research question for this review was “What is known in the literature about how services, systems and policies affect community mobility of MD users?” The sub-questions were (a) “What services, systems and policy factors (barriers and facilitators) relevant to community mobility of MD users have been identified in the literature?” and (b) “What are the research gaps in this given field of study?”

### 2.2.2 Identifying and Selecting Relevant Studies

Given the broad focus of services, systems and policies, multiple databases were searched to generate results from different disciplines and identify studies that might answer the research questions (see search strategy in Table 1). A research librarian was consulted when the search strategy was developed and defined. Two separate searches were done, one covering the years 2003 – 2013, and a subsequent follow-up search covering the years of 2014 – 2015. Both searches were limited to articles written in English.

**Table 1: Search strategy**

Evidence database list	PubMed CINAHL Scopus EMBASE ProQuest - Sociological Abstracts ProQuest - Psych INFO ProQuest - Nursing and Allied Health Source ProQuest - Business Collection EI compendex (Compendex and Inspec) Canadian Public Policy Collection Canadian Health Research Collection		
<b>Search terms</b>	<b>List 1</b>	<b>List 2</b>	<b>List 3</b>
Search terms in each list were combined with OR	“system factors” policy, policies, service, services, system, systems, “accessibility policies”, “transportation plan”, “transportation services”, transportation, barrier, barriers, facilitators, facilitator, regulations, regulation, acts, planning, “urban planning”, “convention on the rights of persons with disabilities”, environment, “environmental factors”, “social environment”	“community mobility”, “physical mobility”, “wheeled mobility”, mobility, “moving around”, “community participation”, participation, “life space”	“mobility devices”, “walking aid”, wheelchair, wheelchairs, “assistive devices”, “assistive technology”, “walking devices”, walker, canes, scooter, “mobility disability”, “mobility impairment”, disability, disabilities, limitation, impairment
Across lists the concepts were combined with AND			

### 2.2.2.1 Inclusion and exclusion criteria

The criteria for article inclusion were empirical studies that had some focus on services, systems and policies (as defined by the ICF) affecting community mobility (or the act of going between places within the community) of adults using mobility devices (18 years and older using wheelchairs, walkers, canes, scooters etc.). Preferably, the focus on services, systems and policies was in the article's objectives. If not, the influence of services, systems or policy factors on community mobility of MD users had to be present in the findings section of the article, even though the objective of the article was to study something else, such as participation or wheelchair use.

Articles were excluded if they focused on children, MD acquisition, or if the attention was on use of MD solely in the home. Furthermore, as there is interaction among different environmental factors within the ICF, articles were excluded if the role of services, systems and policies on community mobility could not be distinguished from the role of other environmental factors. For example, if snow or curbs were mentioned as barriers, the articles were only included if they indicated that those barriers were caused by services, systems and policies (for instance snow removal or architecture services). If any uncertainty persisted regarding article selection after multiple reads, the article was excluded.

### 2.2.2.2 Selecting articles

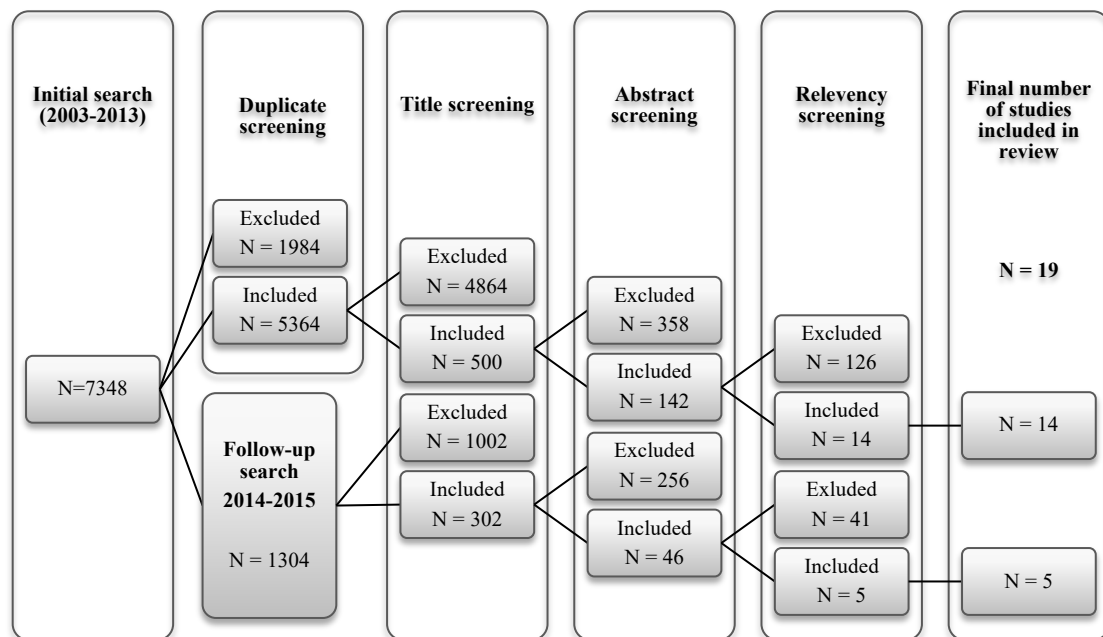
Articles from the search were uploaded to a data selection and management software program called DistillerSR (Evidence partners, 2015). The first two steps in article selection were title- and abstract screening, where articles were excluded only if they clearly were not about environmental factors, community mobility, and people using mobility devices. The abstract screening was done by two reviewers and any discrepancies were discussed between them until agreement was reached. When a decision to include an article could not be made with title and abstract screening, the full text of the article was reviewed to determine relevancy.

A third step involved a relevancy screen, using the inclusion and exclusion criteria to select the articles that were relevant to answer the research question. In the relevancy screening the first author read the full text of remaining articles to determine if there was an explicit discussion of the role of services, systems and policies on community mobility for MD users in the article. Articles were only included if they were determined to identify barriers or facilitators that fall clearly within the ICF's services, systems and policies.

Following the selection assessment, 19 articles were included in the review after all screening phases had been conducted (see Figure 3). However, only six of them focused specifically on services, systems and policy factors affecting community mobility. The

others touched on those aspects in their findings section even though the goal was to study something else, such as participation or accessibility. We did not do quality assessment at this stage as a scoping review has a broad focus with the aim to get an overview of a certain research area (Arksey & O'Malley, 2005), and an assessment might have excluded some of the more focused studies.

**Figure 3: Study selection flow chart**



### 2.2.3 Charting the Data and Collating, Summarizing and Reporting the Results

The first author used a Microsoft Excel spreadsheet, organized following the ICF, for extracting, organizing and analyzing the data from the articles. Barriers and facilitators that could be located within the services, systems and policy category of the ICF (containing 19 subcategories) were identified in the articles (World Health Organization, 2001). Information was also collected about year of publication, country of origin, journal, researcher's background, focus of research, methods of study and targeted population. These data were then reviewed and discussed with the second author. As most of the included studies did not specifically aim to look at the services, systems and policy aspect of mobility, information about how barriers and facilitators were identified within the studies was also collected by recording the kind of questions participants responded to, or the assessments researchers used. Frequency counts were used to report the data within the extracted categories.

## 2.3 Findings

The findings from this review are organized into two categories: (a) Study demographics, and (b) services, systems and policy factors. An overview of the included studies, their demographics, and identified services, systems and policy factors (barriers and facilitators) is presented in Tables 2 and 3.



**Table 2: Demographics and summary of content of included studies**

<b>Authors (year), country, Journal, [Background of first author]</b>	<b>Aim of study / [Focus of study]</b>	<b>Data collection / Whose voice is heard in data</b>	<b>Services, systems and policies (SSP) factors: SSP Barriers [ICF coding] SSP Facilitators [ICF coding]</b>	<b>How were those factors identified?</b>
Hoenig et al. (2003), USA, <i>Journal of the American Geriatric Society</i> , [Medicine]	To identify factors associated with activity restriction among wheelchair users / [IF]	Telephone interview, Face-to-face interview / <i>Wheelchair users</i>	B: Lack of available transportation [e540] F: N/A	Only one sentence about barriers in findings. Questions participants were asked are unknown.
Reid et al. (2003) Canada, <i>American Journal of Occupational Therapy</i> , [OT]	To examine the ways in which mothers who use wheelchairs experience homemaking, and how they shape and respond to their home environments / [IF]	Face-to-face interview / <i>Mothers with disabilities who use wheelchair</i>	B: Institutional barriers to make changes for housing (automatic door openers), Inaccessible environment in public places, Condition of sidewalks (snow, poorly shoveled, issues with transportation schedule [e515, e520, e525, e540] F: N/A	Participants were asked about their experiences as wheelchair users – Included questions about neighborhood and community
Wessels et al. (2004), The Netherlands, <i>Clinical Rehabilitation</i> , [REHAB]	To answer the questions: What are the problems encountered by people with outdoor mobility disabilities? What solutions are being offered to them in the	Interviews / <i>People with outdoor mobility disabilities</i>	B: N/A F: Shared taxi service, MD, combination of several devices and services, such as appropriate MD and shared taxi service [e540, e575, e598/e599]	After analyzing data from participants, facilitators were identified by the researcher (not by participants)

	Netherlands? How effective are these solutions? How responsive is the IPPA instrument (Individually Prioritized Problem Assessment)? / [IF, SSP]			
Hedberg- Kristensson et al. (2007), Sweden, <i>Disability and Rehabilitation: Assistive Technology</i> , [OT]	To increase the knowledge of older persons' experiences of using MD. / [MDO]	Focus groups / <i>Older persons using MD</i>	B: Lack of MD, Long waiting time to get MD, physical environment (condition and design) [e515, e520, e575] F: Support of local authorities (supply of MD) [e575]	Participants were asked about experiences of use of MD
Arthanat et al. (2009), USA, <i>American Journal of Occupational Therapy</i> , [OT]	To measure Usability of power wheelchairs from a multicontextual perspective / [MDO, IF]	Pilot version of the Usability Scale for Assistive Technology: Wheeled Mobility was used / <i>People who use powered wheelchair</i>	B: Inaccessible environment in the community (bad design), bad condition of streets and sidewalk, Lack of availability and accessibility of transportation, Legislation/ mandated standards not rightfully implemented in public places [e520, e540, e598/e599] F: N/A	Usability Scale for Assistive Technology: Wheeled Mobility used with participants. Included questions about environment, or barriers and facilitators
May et al. (2010), Australia, <i>Ageing and Society</i> , [OT]	To investigate the meaning that older people attribute to having an electric mobility- scooter as well as the factors that influence and impact on their purchase and use. / [MDO, IF]	Survey, Focus groups / <i>Older people who use mobility scooters</i>	B: Accessibility issues (buildings, footpaths and community places) both condition and design that need to be solved at system level, issues with inaccessible public transportation, [e515, e520, e540] F: Shared taxi service, MD, combination of several devices and services [e515, e520]	Participants were asked about their experience of problems with using MD

Evcil (2009), Turkey, <i>Disability and Rehabilitation: Assistive Technology</i> , [Architect]	To assess the accessibility of public buildings for physically disabled people in the case of Istanbul. / [Acc]	Questionnaire to collect the data from direct observation and measurement. / <i>The researcher</i>	B: Inaccessible public transport (buses, subways and subway stations), lack of accessible transportation that goes to public places/buildings, and physical environment (design, condition etc.) [e515, e520, e540] F: N/A	Researcher filled out questionnaire. No participants.
Poria et al. (2010), Israel, <i>Journal of Travel Research</i> , [Tourism development and/or management]	To focus on the flight experiences of disabled people, seeking to find ways of making their flight experiences not only more accessible but also more humane and pleasant / [Acc, IF, SSP]	Face-to-face interviews / <i>Disabled people</i>	B: Accessibility issues in airplanes, crew in airplanes not sufficiently trained in how to assist wheelchair users, attitudes/disrespect of crew lack of on-board first aid accessories (bottles for urine, diapers, wet wipes etc., [e515, e540, e585] F: When travelling by air - special vehicle to go through the airport, spacious sitting space in airplane, Appropriately trained crew [e520, e540, e585]	Participants were asked about flight and airport experiences – Included questions about barriers and facilitators and recommendations.
Kántor-Forgách, (2010), Hungary, <i>World Academy of Science, Engineering and Technology</i> , [Transport Policy and Economics]	To provide an overview and make conclusions on the current Hungarian situation in terms of accessibility of the present public transport systems and to reveal the reasons for its deficiency in order to propose steps to solve them / [Acc, SSP]	National statistical sources, direct information from transport operators, documentation (recommendations, reports, policy messages). / <i>Public documents and transport operators</i>	B: Inaccessible public transport, delay in law making regarding accessibility, lack of financial resources to fix accessibility issues, local authorities responsible for making bus stops accessible but only some of them pay enough attention to the accessibility and finance such investments. [e540] F: Legislation that requires accessibility, Co-operation between stakeholders, Forward planning, Ensuring full accessibility, Disability awareness training (transportation staff) free services for people who cannot use public transport [e515, e520, e575, e585]	SSP factors identified from data by researchers. No participants.

Hjelle & Vik (2011), Norway, <i>Disability and Rehabilitation</i> , [OT]	To explore how people with a disability experience participation in society, and to contribute to the understanding of the concept of participation in terms of the ICF / [IF]	Focus groups / <i>Adult wheelchair users</i>	B: Expensive special transport service, Limited freedom to choose, not treated equally by the municipality, reduced public service, inaccessible physical environment and local authorities are responsible for it. [e520, e540, e575] F: Local authorities can make the physical environment accessible and provide services, Good interaction and collaboration with service providers and planners (design and services) [e520, e575]	Participants were asked about experience of participation
Layton (2012), Australia, <i>Rehabilitation Research and Practice</i> , [OT]	To identify consumer perspectives regarding barriers and facilitators to optimal mobility for a heterogeneous population of impaired people who use assistive technology in their daily lives / [IF]	Survey / <i>Assistive technology users</i>	B: Lack of funding from government, lack of accessible and available public transport, need for universal design and physical access to environments, inaccessible public space, infrastructure (accessibility initiatives do not translate into a realistic solution). [e515, e520, e540, e570] F: N/A	Participants were asked about barriers and facilitators to community mobility
Mortenson et al. (2011), Canada, <i>Sociology of Health &amp; Illness</i> , [OT]	To understand the culture of wheelchair use in residential care settings / [MDO]	Fieldwork, participant observation, in-depth individual interviews and review of relevant institutional policy documents. / <i>Wheelchair users in a residence, family members, staff</i>	B: Booking transportation with two days notice, accessibility issues in public transportation, inaccessible physical environment (bad design and bad condition), finances [e515, e520, e540, e570] F: N/A	Participants were asked questions about their experiences and about their activities, places they go to and assistance they get.
Hammel et al. (2013), Canada/USA, <i>Disability and</i>	To compare and contrast the perspectives, issues and	Focus groups / <i>Disabled people, family members, caregivers,</i>	B: Physical environment – Condition; Accessibility to transportation; Policies regarding transportation services/accessibility etc.; Access to information across systems.	Participants were asked questions about their

<i>Rehabilitation: Assistive Technology</i> , [OT]	priorities of multiple stakeholders in the USA and Canada related to MD access, use and outcomes. / [MDO, IF]	<i>professionals involved in assistive technology service delivery</i>	Issues with repairing MD; Lack of funding for MD acquisition and repair; Issues related to training of MD (funding, quality); Quality and communication issues with service providers (vendors/professionals); Funding and system policy issues related to MD delivery; Lack of coordination across different systems; Political and economic influences of access and funding of MD [e520, e540, e575, e598/e599] F: Physical environment - Condition, Accessibility to transportation, Policies regarding transportation services/accessibility etc., Access to information across systems, funding for MD acquisition and repair, economic [e520, e540, e575, e598/e599]	experience of MD use and outcome.
Ferrari et al. (2014), UK, <i>Transportation Research Part C</i> , [TEC/ENG]	To present a method that uses network science and spatio-temporal analysis to rank stations (rail, tram, boat and bus) in a way that minimizes the divergence between accessible and non-accessible routes. / [Acc, SSP]	Information about the transportation network in London / <i>The researcher</i>	B: Transportation services – lack of accessibility increases the number of interchanges (such as transfers between tram and bus) and those transfers takes them longer time than others, which results in longer travel times and their journeys become longer [e515, e540] F: N/A	SSP factors identified by researcher from the data. No participants.
Pettersson et al. (2014), Sweden, <i>Scandinavian Journal of Occupational Therapy</i> , [OT]	To describe how men and women experience their use of powered wheelchairs and powered scooters in everyday occupations, in the home and in society at large. / [MDO]	Focus groups / <i>Users of powered MD</i>	B: Inaccessible public transport and lack of information regarding transportation services [e515, e540] F: Service providers, administrators, politicians and general public knowledge about accessibility. Involvement of powered wheelchair users and occupational therapists when new buildings and places are planned. Better cooperation to improve accessibility [e515, e520, e585]	Participants were asked about their experiences of MD use for different occupations and in different environments. – Included questions about barriers and facilitators

Korotchenko & Clarke, (2013), Canada, <i>Disability &amp; Society</i> , [Kin]	To examine older Canadian adults' experiences of utilizing power wheelchairs and motorized scooters in the context of the built environment. / [MDO]	In-depth, qualitative interviews / <i>Power mobility users</i>	B: Accessibility issues with public transportation [e515, e540] F: N/A	Participants were asked questions about MD use – Included questions about barriers and facilitators
Ripat et al. (2015), Canada, <i>Archives of Physical Medicine and Rehabilitation</i> , [OT]	To identify winter weather issues of the greatest impact on wheeled MD users' community participation. / [IF, SSP]	Online survey / <i>Wheeled MD users, or their caregivers</i>	B: Accessibility to transportation services, winter issues such as snow clearing [e520, e540] F: Responsibility for winter related issues should be shared among stakeholders (government officials, policymakers, public transportation policies, health care providers, wheelchair vendors and manufacturers) [e520, e540, e575, e598/e599]	Questions in a survey were organized around the 5 environmental domains of the ICF including SSP
Almada & Renner, (2015), Brazil, <i>WORK</i> , [Design]	To identify ergonomic and accessibility issues faced by wheelchair users and persons with mobility impairments when using public transport, from a user perspective. / [Acc, SSP]	Open ended interview, questionnaire and field observation / <i>Wheelchair users</i>	B: Transportation services - waiting time, schedule, service quality, insufficiently trained employees [e540, e585] F: N/A	Participants were asked about their experiences of using public transport services – included questions about accessibility, safety, stability etc.
Mortenson et al. (2015), Canada, <i>Scandinavian Journal of Occupational Therapy</i> , [OT]	To understand the mobility choices of community-dwelling, power wheelchair users. / [MDO]	Open ended interviews / <i>Community dwelling older, power wheelchair users</i>	B: Insufficient snow removal, and funding policies for powered wheelchairs [e520, e570] F: Training for users on how to use transportation [e540, e585]	Participants were asked about their experiences of MD use – Included questions about barriers

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*List of Abbreviations: MD = mobility devices; Column 1: OT=Occupational Therapy, KIN = Kinesiology, TEC/ENG = IBM Technology / engineering, REHAB = Rehabilitation research;*  
*Column 2: MDO = Mobility devices outcome/use, IF = Influencing factors on MD use and/or activity/participation, Acc = Accessibility/physical environment, SSP = services, systems or policies on community mobility of MD users; Column 4: B=barriers, F=Facilitators*

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**Table 3: Subcategories and codes of ICF's services, system and policies identified in this review**

Subcategories within the services, systems and policies category of ICF*	ICF code for each subcategory	subcategories identified in this review
...The production of consumer goods	e510	
...Architecture and construction	e515	x
...Open space planning	e520	x
...Housing	e525	x
...Utilities	e530	
...Communication	e535	
...Transportation	e540	x
...Civil protection	e545	
...Law	e550	
...Associations and organizations	e555	
...Media	e560	
...Economic	e565	
...Social security	e570	x
...General social support	e575	x
...Health	e580	
...Education and training	e585	x
...Labour and employment	e590	
...Politics	e595	
...Other	e598/e599	x

\*For further details on each subcategory, see ICF (World Health Organization, 2001, pp. 192-207)

### 2.3.1 Studies Demographics

The 19 included studies originated from five regions: North America (N = 8), Europe (N = 6), Australia (N = 2), South America (N = 1) and Middle East (N = 2). The majority of the articles were from the years 2009-2015 (N = 15). The first authors of 11 articles have an occupational therapy background. Three other first authors have different health care background, three have architecture/design/engineering backgrounds, one comes from tourism development and management, and one had a background in transport policy and economics (see Table 2). The majority of the articles come from journals that focus on rehabilitation or health-related subjects (N = 15).

### 2.3.2 Services, Systems and Policy Factors

Two studies focused specifically on services, systems and policies in relation to public transportation for people with reduced mobility (Ferrari, Berlingiero, Calabrese, & Reades, 2014; Kántor-Forgách, 2010). One study looked at accessibility in the Hungarian public transport system from a policy perspective (Kántor-Forgách, 2010). The other was conducted in the United Kingdom and examined transportation systems and networks in London in terms of travel time and transfers for MD users (Ferrari et al., 2014).

Four studies investigated services, systems and policy factors as an aspect of their aim (Almada & Renner, 2015; Poria, Reichel, & Brandt, 2010; Ripat, Brown, & Ethans,



2015; Wessels, De Witte, Jedeloo, van den Heuvel, & van den Heuvel, 2004). Poria et al. (2010) conducted a qualitative study exploring disabled people's flight experiences, Ripat et al. (2015) completed an online survey identifying winter weather issues for wheelchair and scooter users, Almada and Renner (2015) undertook a mixed methods study looking at ergonomics and accessibility issues when using public transport, and Wessels et al. (2004) performed a quantitative study looking at barriers encountered by people with mobility impairments and solutions offered in the Netherlands. All the other studies (n = 13) identified some services, systems and policy factors' influence on community mobility of MD users in their findings section, but their objective was to study other aspects, such as participation, wheelchair use, or accessibility (see Table 2).

The ICF divides the services, systems and policy factors into 19 subcategories (World Health Organization, 2001). In this review, barriers or facilitators were identified from eight of these ICF subcategories: transportation, open space planning, architecture and construction, social security, general social support, education and training, housing, and other (see Table 3).

Sixteen studies identified barriers to community mobility for MD users within two or more subcategories (see Table 2). All the studies except one identified barriers. The most frequent barriers identified were with transportation (N = 17), such as inaccessible public transportation, lack of availability of transportation service, and issues regarding

scheduling and cost of transportation service. Other common barriers included open space planning (N = 11), and architecture and construction (N = 10), such as when the condition of sidewalks, or design of the built environment hinders mobility. Less common barriers identified fell within the following categories: social security (N = 3), general social support (N = 3), other (N = 2), education and training (N = 2), and housing (N = 1). The social security barriers were related to lack of financial support from government. General social support barriers included reduced public services, and issues with the acquisition of mobility devices. In the category *other* were barriers such as lack of information and coordination between different systems, or the lack of implementation of mandated standards in public places. Barriers related to education and training included insufficiently trained service providers, and within the housing category were institutional issues for making home modifications.

Ten studies identified some services, systems and policy factors that can facilitate community mobility of MD users, in the following categories: open-space planning (N = 7) general social support (N = 6), transportation (N = 5), architecture and construction (N = 3), education and training (N = 2) and other (N = 4) (see Table 2). The facilitators within the open-space planning category were linked to implementation of accessibility legislation, involvement of stakeholders in design processes, and raising accessibility awareness throughout society. The general social support facilitators were mainly related to the process of acquiring mobility devices, as well as regarding communication and

cooperation between service providers. Facilitators in the transportation category were primarily about supportive transportation policies, and accessible and affordable means of transportation. The facilitators within the *other* category were related to access to information between different systems, combination of several services and devices, and cooperation and shared responsibility among different stakeholders.

## 2.4 Discussion

The topic of services, systems and policies affecting community mobility of MD users is very broad, but few articles were found to answer the research question. Only six of the included studies planned to explore services, systems or policy factors, which reveals that there is limited knowledge generation about how those factors affect community mobility for this population.

Both of the studies in this review that specifically focused on a phenomenon that is part of the ICF's services, systems and policies (i.e., Ferrari et al., 2014; Kántor-Forgách, 2010) were quantitative in nature and put emphasis on accessibility for people with reduced mobility and how accessibility is affected by the transportation systems and policies. This emphasis matches with the dominating factors identified in this review; those involving transportation, open space planning, and architecture and construction.

The majority of the studies reviewed did not specifically address services, systems and policy factors in their objectives. Most of these studies were qualitative studies asking participants about their experiences of using mobility devices or participating in society. Interestingly, services, systems and policy factors to community mobility were identified by participants who were not responding to questions that specifically targeted this infrastructure, which suggests the importance MD users place on these factors.

The increase in the number of studies published after the year of 2008 suggests a gradual shift in focus that may be related to both the ICF and the CRPD. In 2001, environmental factors, such as services, systems and policies, were integrated into the ICF (World Health Organization, 2001), which may have prompted practitioners and researchers to think about and include these factors in their work. Furthermore, this shift corresponds to ideas represented in the CRPD that was adopted by the UN General Council in 2006 and obligated its member states to create equal opportunities for all people (United Nations, 2006), bringing these environmental factors to the forefront. The CRPD has been widely discussed and has influenced ideas about rights of disabled people and how the infrastructural system, such as services, systems and policies, can be responsible for limiting the opportunities of disabled people to fully participate in the society, instead of blaming mainly the impairments with which they live. This shift in focus suggests that stakeholders are more aware of the rights disabled people have and society's responsibilities to move things forward for the group.

Despite this potential shift, surprisingly few policy-oriented articles were found for this review. This finding raises the question of why the issue of community mobility of MD users has not been looked at within the policy research field. The majority of the reviewed studies had a first author with an occupational therapy background, which reflects the occupational therapy interest and practice of recommending mobility devices for persons with participation restrictions, and addressing environmental factors that affect people's occupations, such as community mobility. One possible explanation is that most occupational therapists lack the expertise to analyze policy. Consequently, their research does not include a critical exploration of existing policies, their implementation and influence. While community mobility of persons who use mobility devices is a topic of interest to occupational therapy researchers, the lack of literature on it from a policy perspective suggests that it is not of interest to researchers with this expertise. Yet, such analysis may further our understanding of the relationship between community mobility and services, systems and policies, and potentially shed light on what needs to change to move things forward for MD users to promote their community mobility.

#### 2.4.1 Future research

Further research is needed to obtain a more in-depth and precise understanding of the topic, targeting specifically the impact of services, systems and policies on MD users and their opportunities to move around within their communities. In particular, more details

are needed on the specific services, system and policy factors identified in this review, such as those relating to transportation, open space planning, and architecture and construction. Multiple aspects could be explored, for instance how different transportation services or accessibility initiatives shape community mobility for this group, or how involvement of stakeholders in governmental policy development can affect systems and services that are intended to support community mobility for this population. Furthermore, it would be interesting to obtain a deeper understanding of how integration, or coordination, between different service areas can better support community mobility for MD users. Last, involving stakeholders in the research process, such as service users, providers, and policy makers, would enrich our understanding of broader contextual elements that influence services, systems and policies affecting community mobility.

#### 2.4.2 Study limitations

The topic of this review - services, systems and policies affecting community mobility of MD users - is very broad and made the search for articles challenging. Because of this breadth of the subject, there is a possibility that some relevant studies were not found, which might limit the scope of the findings. We tried to counter this limitation by using multiple databases and working with a research librarian to develop a comprehensive search strategy.

The number of articles included initially in the title and abstract screening was large, so the possibility that some relevant articles were excluded at that stage cannot be ruled out. Furthermore, the process of selecting relevant articles was a subjective process. Even though the boundaries between different environmental factors of the ICF are quite clear in the framework, they interact with each other in real life. Consequently, article selection, data extraction and data analysis were challenging processes that required the first author of this paper to interpret the article's focus on environmental factors and their coherence with ICF's services, systems and policies. Therefore, seeking the opinion of an expert, not involved in the project, on the extent to which relevant articles were included in the final selection might have strengthened the results.

Another limitation is that the scope of this review was restricted to English literature, perhaps excluding important studies from non-English journals and favouring a Western view on the subject. Using other search techniques, such as reviewing the reference list of included articles might have revealed additional studies to include, and relevant unpublished studies might have been missed because grey literature and policy evidence were not included in the review.

## 2.5 Conclusion

This scoping review explored what is known in the literature about the influence of services, systems and policies on community mobility of MD users. Certain factors, for instance transportation, open space planning, and architecture and construction, were identified as factors that may either hinder or facilitate community mobility, but deeper knowledge is needed on the relationship between those factors and MD users' community mobility. The results show that there is a lack of attention paid to services, systems and policy factors in the research literature which limits the knowledge on the subject.

## 2.6 Key Messages

- Little attention has been paid to how services, systems and policies influence community mobility for MD users, which limits the ability to understand and articulate this relationship.
- More precise information is needed on specific services, systems and policy barriers and facilitators shaping community mobility of MD users, such as transportation, open space planning, and architecture and construction.



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## Chapter 3

### 3 Applying case study methodology to occupational science research<sup>2</sup>

The complexity of human occupation is demonstrated in many definitions of the term. For instance, the International Society of Occupational Scientists defines occupation as the “various everyday activities people do as individuals, in families and with communities to occupy time and bring meaning and purpose to life... [including] things people need to, want to and are expected to do” (n.d., p. 1). Occupation has further been described as “an important mode through which human beings, as organisms-in-environment-as-a-whole, function in their complex totality” (Dickie, Cutchin & Humphry, 2006, p. 83), emphasising how occupation cannot be isolated from its context. Other authors have highlighted the need for going beyond understanding occupation at the individual level, as multiple contextual factors shape occupation, including socio-political factors (Josephson, 2017; Rudman, 2013). Thus, to understand occupation, it is

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necessary to take into account the complex interplay of people, their occupation, and context.

Consequently, to study occupation, methodologies are needed that can capture the complexity of that phenomenon. Methodology can be thought of as the process of doing research (Creswell, 2012; Lincoln, Lynham, & Guba, 2011), including the data collection and analysis methods, as well as the underpinning assumptions guiding researchers in that process (Taylor, 2013). In recent years, scholars within the occupational science field have explored and discussed various research methodologies with applications to study human occupation, e.g. visual methodologies, grounded theory, phenomenology, critical policy analysis and more (Hartman, Mandich, Magalhães, & Orchard, 2011; Nayar, 2012; Nayar & Stanley, 2015; Park Lala & Kinsella, 2011; Pereira, 2014). We believe case study methodology to be one of those. Although this approach has been identified as useful “to understand the complexities of occupation, as a phenomenon embedded in the messiness of people’s everyday lives” (Jones & Hocking, 2015), it seems to have gained little attention within occupational science.

Researchers may have difficulties seeing the potential of case study methodology for the study of occupation due to the vague and inconsistent use of the term “case study”, and divergent publications on the topic (Hyett et al., 2014; Sandelowski, 2010). Sometimes the term stands for a methodology (Creswell, 2012; Flyvbjerg, 2011; Merriam, 1997;



Simons, 2009; Stake, 1995; Taylor & Francis, 2013; Yin, 2014), but often for vignettes of clinical or teaching cases (Fitzgerald, Ratcliffe, & Blythe, 2012; Hamel, Dufour, & Fortin, 1993; Louie, 2012; Misko, Nelson, & Duggan, 2014), or as a synonym for qualitative work (George & Bennett, 2005).

To respond to the interest within the occupational science field to explore different methodologies that can guide research in the field, this paper is divided into two phases. The first provides an overview of case study methodology, and the second presents a review of how case study methodology has been used for the study of occupation. Following these two sections is a discussion about the methodology's further potential for the study of occupation.

### 3.1 Case study methodology

The purpose of this phase is to explain what case study methodology is and to set the scene for part two. The synthesis of the literature took place through extensive and in-depth reading of existing literature on case study methodology. The work of several prominent authors (Merriam, 1997; Simons, 2009; Stake, 1995; Yin, 2014) dominate the case study literature, and therefore, synthesis of their approaches prevailed in this phase, while also drawing on other authors.

Drawing on the essence of common definitions of case study methodology, we posit it is an in-depth study of a bounded phenomenon (a case) in its real-life context. The approach is useful to look at a specific case (or cases) from various perspectives, study the complexity and particularity of a case(s), and gain a comprehensive understanding of it (Merriam, 1997; Simons, 2009; Stake, 1995; Yin, 2014). Although the most cited authors' approaches differ slightly, they share assumptions and common characteristics that guide case study research. All of these characteristics are important to incorporate within case study research, and will be described in the following sections.

### **3.1.1 Assumption 1: Connection between a case and its context is inseparable and complex**

In case study research, the unit of analysis, or what is being studied, is a case or cases. A case has been described as a bounded system (Merriam, 1997; Stake, 1995), a concrete entity or a phenomenon in context (Merriam, 1997; Yin, 2014). Stake (1995) further stated that a “case is a specific, complex, functioning thing” (p. 2). Commonly, in case study research, a case consists of an individual. Cases can be other phenomenon as well, such as groups, partnerships, communities, specific events, organisations, institutions, programs, policies, relationships, projects, processes, procedures, and decisions (Merriam, 1997; Simons, 2009; Stake, 1995; Swanborn, 2010; Yin, 2014). Examples include a study of the services, systems, and policies that can restrict or support

community mobility for people with mobility impairments in the town of Akureyri, Iceland (Jónasdóttir, Egilson, & Polgar, 2018), and a study about a community-based partnership to promote healthy and active living in a Canadian community (Misener & Misener, 2016). To limit the research scope, boundaries for the case are identified, such as temporal, spatial, or other concrete parameters (Simons, 2009; Yin, 2014).

The case and its boundaries are usually defined at the beginning of the research process, but the methodology allows modifications as researchers learn more about the case and its context (Simons, 2009; Stake, 1995; Yin, 2014). Definitions of cases depend on the research questions that are posed (Simons, 2009; Swanborn, 2010; Yin, 2014). A case study approach has been suggested as suitable to answer “how” and “why” questions where the focus is on processes (Yin, 2014), or “what” questions that are intended to understand the case (Merriam, 1997).

### 3.1.2 Assumption 2: Need for multiple viewpoints

Use of multiple sources of data, such as observations, interviews, documents, archival records, and/or physical artefacts characterises data collection in case study research (Merriam, 1997; Simons, 2009; Stake, 1995; Yin, 2014), embracing the pluralistic idea that a case should be studied from various viewpoints in the attempt to gain comprehensive understanding of it (Baxter & Jack, 2008; Berg & Lune, 2012; Jensen & Rodgers, 2001; Merriam, 1997). Some case study researchers prefer to use only

qualitative methods (Merriam, 1997; Stake, 1995), while others also advocate for use of mixed methods (Bryman, 2012; Flyvbjerg, 2011; Simons, 2009; Woodside & Wilson, 2003; Yin, 2014). The objective of the study, along with the research questions and theoretical framework will shape the data collection and analysis plan for each study (Merriam, 1997; Simons, 2009; Stake, 1995).

Descriptions of data analysis within case study research is especially lacking in the literature (Simons, 2009; Yin, 2014). Data analysis can take place at three levels. Level one involves analysing data from each source separately (Yin, 2014), helping to narrow down the scope of the study and guide further data collection. Level two, the overall analysis of a case, is essential in every case study and includes data from all sources (Baxter & Jack, 2008; Creswell, 2012; Merriam, 1997; Simons, 2009; Yin, 2014). A cross-case analysis, level three, is used in a multiple case study, when comparing or synthesising findings from all cases, after analysing the cases independently (Creswell, 2012; Merriam, 1997; Stake, 1995; Yin, 2014).

### 3.1.3 Assumption 3: Creative and flexible approach

There is consensus that case study methodology is flexible regarding the paradigmatic stance of the researcher (Merriam, 1997; Simons, 2009; Stake, 1995; Yin, 2014); it is “a bridge that spans the research paradigms” (Luck, Jackson, & Usher, 2006, p. 105). For example, Stake (1995), Merriam (1997) and Simons (2009) all use a constructivist

perspective in their research, while Yin (2014) seems to align closer to post-positivism (Hyett et al., 2014; Yazan, 2015) or a pragmatic perspective (Creswell, 2012).

Case study research requires creativity, as depending on the researcher's paradigmatic stance, the purpose of study, and its theoretical foundation and research questions, one can choose between a variety of methods for data collection and analysis. The approach further requires flexibility, as in this iterative process things can change as the researchers get to know more about the case and its context. For example, the research questions commonly start rather broad, but may change and become more precise later in the process (Merriam, 1997; Simons, 2009; Stake, 1995; Swanborn, 2010; Yin, 2014).

In addition, case studies may be categorised into different types. The most common depends on the number of cases under study, that is either *single* or *multiple* case studies (Merriam, 1997; Stake, 1995; Yin, 2014). Other types are based on: (a) purpose or intent of study (e.g. exploratory, descriptive, explanatory (Yin, 2014), evaluative (Simons, 2009; Stake, 1995), interpretive (Merriam, 1997) or theory-generating (Simons, 2009)); (b) case selection (such as intrinsic or instrumental) (Stake, 1995); or on (c) disciplinary orientation or tradition (e.g. ethnographic, historical, psychological, or sociological) (Merriam, 1997; Simons, 2009).

### 3.1.4 Assumption 4: Value of knowledge depends on the context of both the research and readers

An important feature of case study reports is rich or thick description of both the case and its context (Baxter & Jack, 2008; Flyvbjerg, 2011; Hancock & Algozzine, 2011; Merriam, 1997; Simons, 2009; Stake, 1995; Swanborn, 2010; Yin, 2014), in order to “take the reader into the case situation” (Merriam, 1997, p. 328). Furthermore, as doing case study requires creativity and flexibility, it is important that the outcome of the study is transparent, by providing detailed and explicit description of all aspects of the study design and process, such as paradigmatic stance, research questions, case selection and bounding, data collection and analysis. This level of detail, however, can be challenging within the text limitations of traditional journal articles (Hancock & Algozzine, 2011; Simons, 2009; Swanborn, 2010).

### 3.1.5 Summary

Case study methodology offers a creative and flexible way to get a deep understanding of human complexities in context, using various means to collect data. It is important to keep in mind that certain aspects are essential in case study research, but other aspects are more flexible and depend on paradigmatic perspectives, preferences of the researcher, and other considerations (see Table 4).

**Table 4: Essential and flexible aspects of case study research**

	Aspects of case study research	Characteristics of each aspect
<b>Essential aspects</b>	Unit of analysis is a bounded case, in its real-life context	Clear description of a case and its context - but its definition may change during the research process
	Use multiple sources of data (qualitative or mixed)	Observations, documents, interviews, archival records, physical and/or artefacts
	Transparency of the output/report	All decisions and actions in the research process are made explicit for the readers
<b>Aspects that are flexible</b>	Paradigmatic stance	Post-positivism, constructivism, pragmatism, other
	Research question	How, why, what...?
	Selection of case(s)	Multiple approaches and rationales
	Types of case study	Based on number of cases, purpose of study, case selection, or disciplinary orientation
	Data analysis methods	Many strategies to choose from

### 3.2 Case studies within the study of occupation

Part two presents a review of the occupational science and therapy literature, guided by the following research question: How has case study methodology been used within the fields of occupational science and occupational therapy to study occupation? An integrated review methodology (Whittemore & Knafl, 2005) was used for this review as it can serve to analyse methodological issues within an area of study. The approach involves five stages: (1) problem identification, (2) literature search, (3) data evaluation,

(4) data analysis, and (5) presentation. The first stage is covered above in the introduction section; stages two to five are described in the following sections.

### 3.2.1 Literature search stage

A librarian was consulted to help identify the most appropriate search strategy. Relevant articles were searched in four electronic databases, using a combination of the search terms. Searching was limited to research articles that were published in English and available online through the library of Western University. The search terms and number of articles found in each data base is shown in Table 5.

**Table 5: Search strategy**

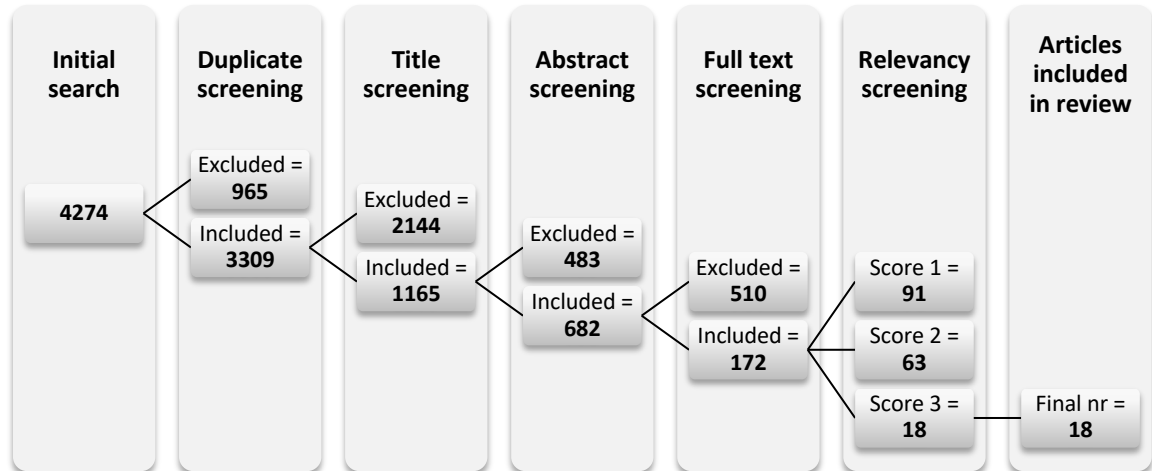
Search terms	Data bases	Articles #
“Case study” OR “Case studies” OR “Case study method*” OR “Case study methodology” OR “Case methodology” OR “Case method*” OR “Case study research” OR “Case research” OR “Case approach” OR “case study approach” OR “Case design” OR “case study design” <b>AND</b> “Occupational science” OR “Occupational therapy” OR “study of occupation” OR “occupation”	CINAHL	650
	ProQuest Nursing & Allied Health Source	259
	SCOPUS	1998
	EMBASE	1367

The data selection and management software program DistillerSR (Evidence Partners, 2015) was used to remove duplicates, and do title- and abstract screening. Full text of articles was screened when needed. The criteria for article inclusion were empirical



studies using case study methodology/design (as identified by the articles' authors) focusing on occupation. The articles had to have some connection to either occupational science or occupational therapy, such as be published in relevant journals, the author(s) identify themselves as within the occupational science or therapy fields, or the articles refer to occupational science or therapy literature, concepts, or models. Articles were excluded if they were methodological or review papers, or if they were illustrations of clinical vignettes from clinical practice. Following this screening process, 172 articles remained in the pool of potential articles (see Figure 4).

**Figure 4: Study selection flow chart**



### 3.2.2 Data evaluation stage

This stage involved application of relevancy criteria to select the final articles for the review. Full-text of all articles that were still included at this stage were reviewed (n = 172), evaluated and given score on data relevance of moderately, fairly, or very relevant (see Table 6). Articles that met all the criteria for ‘very relevant’ comprised the final pool of articles for the review (n = 18).

**Table 6: Relevancy criteria**

Relevance	Criteria
3 Very relevant	<ul style="list-style-type: none"> <li>• Case study research</li> <li>• References to case study literature</li> <li>• Focus of study is on occupation (such as experience of occupation, relationship to health, or diverse forces shaping occupation)</li> </ul>
2 Fairly relevant	<ul style="list-style-type: none"> <li>• Case study research</li> <li>• References to case study literature</li> <li>• Some focus on occupation, but main focus on intervention process, outcome of occupational therapy intervention, occupational therapy setting, education/training for occupational therapists, thinking or working process of an occupational therapist</li> </ul>
1 Moderately relevant	<ul style="list-style-type: none"> <li>• Authors claim they are doing case study</li> <li>• Some focus on occupation (as in #s 2 or 3)</li> <li>• No references to case study literature, or only to general methodology sources</li> </ul>

### 3.2.3 Data analysis and presentation stages

Information on characteristics of case study methodology, as introduced earlier in this paper, served as a theoretical and practical foundation to guide the data extraction and analysis process. Information about what kind of data were extracted can be seen in Table 7. The analysis, which was a deductive content analysis, occurred concurrently with the data extraction. Each article was read multiple times and data were extracted and recorded in a synthesis matrix using an excel spreadsheet, which allowed for systematic comparison between articles. The extracted data were compared to characteristics of case study methodology to identify commonalities and differences. Questions such as “what are the differences and similarities between the potential use of case study methodology and the ways it has been used for the study of occupation?” guided this comparison.

**Table 7: Extracted information**

<b>Type of data</b>	<b>Extracted information</b>
Citation data	Authors; Title; Journal; Year of publication; Country of origin
Case study information	Case study sources referred to; Type of research questions; Theoretical perspective used; The case(s) and its boundaries; Type of case study; Data collection methods; Data analysis methods, level of analysis; Paradigmatic stance of the researcher(s); Strategies used to enhance quality; Generalisability or transferability identified by authors
Focus of study and its relation to the study of occupation	Objective/purpose of study; Focus of study relation to occupation; Application of findings for occupational science or therapy

### 3.2.4 Findings

Findings from this review are organised into five categories: (1) Study demographics, (2) Design of study, (3) Study focus, (4) The bounded case(s), and (5) Methods. An overview of the data from the reviewed articles can be seen in Table 8.

**Table 8: Overview of data from reviewed articles**

<b>Authors (year), Journal, [Country of origin]</b>	<b>Objective of study / (Type of research questions) [Focus of study relation to occupation]</b>	<b>Type of case study, (multiple or single case study); [Main case study references used], <i>What is the case, / (boundaries)</i></b>	<b>Data collection methods; <i>Data analysis methods</i> [Level of analysis]</b>	<b>Application for Occupational Science (OS) or Occupational Therapy (OT)</b>
<b>Paradigmatic stance of the researcher [Theoretical perspective]</b>			<b>Strategies used to enhance quality</b>	<b><i>Generalisability or transferability of findings</i></b>
George et al. (2001), <i>BJOT</i> , [Australia]	To explore the effect of emotional changes following a stroke on engagement in occupation / (how and what) [ <i>Experience of occupation after trauma</i> ]	Qualitative case study (multiple), [Merriam], <i>Individuals</i> , (criteria for participants)	Interviews (with each case), and case notes <i>Miles and Huberman's approach</i> [within, and a cross-case] Use two sources of data, member checking, use of case study protocol to ensure consistency between cases	Enhances understanding of how trauma affects occupation; Directions for OT. <i>Cannot be generalised</i>
Dale et al. (2003), <i>Work</i> , [USA]	To describe the experience of cumulative trauma disorder symptoms on a family unit / (how) [ <i>Experience of occupation after trauma</i> ]	Single case study (single), [Merriam & Simpson], <i>A couple</i> , (criteria for participants)	Interviews (series of 6 interviews with the couple), and observations <i>Grounded theory methods/coding</i> [within case]	Enhances understanding of how trauma affects occupation; Directions for OT. <i>Cannot be generalised</i>

Interpretivism <i>[Not explicit]</i>			Data triangulation, researcher triangulation, member checking, field notes, input from experts	
Whiteford (2005), <i>CJOT</i> , [Australia]	To understand occupational deprivation as a lived experience / (unknown) <i>[Experience of occupational deprivation in context]</i>	Instrumental case study (Single); [Stake], <i>Individuals</i> , (Not clear)	One interview; <i>Narrative approach</i> [Unknown]	Enhances understanding of occupation; Direction for future research, and towards population-based approach. <i>May be transferred to similar context</i>
Constructivism <i>[Critical social – occupational deprivation]</i>			Unknown	
Yeager (2006), <i>JOS</i> , [USA]	To explore the influence of theater participation on the self- concepts of young adults / (unknown) <i>[Occupation's effects on wellbeing]</i>	Qualitative, interpretive case study (multiple), [Merriam; Yin], <i>Individuals</i> , (criteria for participants)	Observation, and interviews (series of 4-6 with each participant). <i>Constant comparative analysis using analytic induction</i> [Unknown]	Enhances understanding of occupation effects on wellbeing. <i>Cannot be generalised</i>
Interpretivism <i>[Symbolic interactionism]</i>			Thick description, member checking	
Löfqvist et al. (2009), <i>SJOT</i> , [Sweden]	To explore how old women experience the use of mobility devices over time, in relation to everyday occupation / (how) <i>[Experience of occupation in context]</i>	Exploratory case study (multiple), [Yin], <i>Individuals</i> , (criteria for participants)	Survey, interviews and observation <i>Descriptive statistics, and longitudinal and retrospective description</i> [within, and a cross-case]	Enhances understanding of the complex transaction between person, environment and occupation. <i>May be transferred to similar context</i>
Not explicit <i>[The Disablement Process Model, and occupational therapy perspective]</i>			Researcher triangulation, data triangulation, input from experts, thick description	

Wood et al. (2009), <i>AJOT</i> , [USA]	To explore and explain interrelationships among the environment of Alzheimer's special care units and the everyday quality of life of residents / (what, how) [Occupation effects wellbeing]	Instrumental case study (multiple), [Yin], Unknown, (Not clear)	Observation (quantitative method) <i>Quantitative analysis</i> [Unknown]  Training of observers	Results are directed towards (OT) <i>Theoretical generalisability (Yin)</i>
Not explicit [Occupational science perspective]				
Harding et al. (2009), <i>CJOT</i> , [Canada]	To understand how children with disabilities view their participation in out-of-school-time activities in various environmental settings / (how) [Experience of occupation in context]	Collective case study (multiple), [Yin; Stake; Baxter and Jack], Unknown, (Not clear)	Questionnaire, photographs, interviews <i>Descriptive statistics and inductive content analysis approach</i> [within, and a cross-case]  Data triangulation, researcher triangulation, reflexivity, audit trail, input from experts	Enhances understanding of occupation and contextual factors shaping it; Directions for OT <i>Cannot be generalised</i>
Not explicit [ICF and CMOP]				
Shank & Cutchin (2010), <i>JOS</i> , [USA]	To examine how women engage in meaningful occupations in the dynamic relationship of person, aging, and place / (how) [Meaning of occupation in context]	Instrumental case study (multiple), [Stake], <i>Individuals</i> , (criteria for participants)	Interviews (with each individual case) and observation <i>Grounded theory methods/coding</i> [within, and a cross-case]  Data triangulation, researcher triangulation, member checking	Enhances understanding of occupation in a context <i>Cannot be generalised</i>
Not explicit [The perspective of transactional occupation]				
Zimolag & Krupa (2010), <i>OTMH</i> , [Canada]	To explore the occupation of pet ownership as an enabler of community integration / (how and what)	Exploratory case study (single), [Yin], <i>Individual</i> , (criteria for	Interviews, observation, photographs, and documents <i>Grounded theory coding procedures</i> [within case]	Enhances understanding of occupation effects on wellbeing, and

Not explicit <i>[Not explicit]</i>	<i>[Meaning of occupation in context]</i>	the participant)	Researcher triangulation, data triangulation, member checking, thick description	contextual factors shaping occupation. <i>Cannot be generalised</i>
Robinson & Penman (2011), <i>NZJOT</i> , [Aotearoa/New Zealand]	To understand the how and why teachers teach handwriting to year one students / (how and why)	Qualitative instrumental collective case study (unknown), [Yin; Stake], <i>unknown</i> , (Not clear)	Interviews (with 6 individuals) <i>Open coding, and themes</i> [Unknown]	Enhances understanding of occupation; Directions for OT. <i>Cannot be generalised</i>
Not explicit <i>[Occupational lens]</i>	<i>[Experience of occupation in context]</i>		Unknown	
Basiletti & Townsend (2012), <i>BJOT</i> , [Canada]	To explore how working group members experienced decision-making power in group work / (how)	Instrumental embedded case study (single), [Stake; Lincoln & Guba], <i>A group</i> , (Specific group, location)	Interviews, Focus group discussion and public documents <i>Constant comparison method</i> [within case]	Enhances understanding of occupation; Directions for practitioners; some focus on context shaping occupation. <i>May be transferred to similar context</i>
Constructivism <i>[Critical - empowerment]</i>	<i>[Experience of occupation in context]</i>		Data triangulation, member checking, audit trail	
Kylberg et al. (2013), <i>SJOT</i> , [Sweden]	To explore experiences of mobility device use among old men / (unknown)	Longitudinal multiple case study (multiple), [Yin; Creswell], <i>Individuals</i> , (Criteria for participants)	Quantitative data, interviews and observation <i>Descriptive statistics, and narrative approach</i> [within, and a cross-case]	Enhances understanding of occupation; Directions for practitioners; some focus on context shaping occupation. <i>May be transferred to similar context</i>
Not explicit <i>(Occupational therapy, and a social gerontology perspective)</i>	<i>[Experience of occupation in context]</i>		Researcher triangulation, data triangulation	

<p>Evans et al. (2014), <i>SJOT</i>, [Australia]</p> <p>Not explicit [<i>The Model of Juggling Occupations (based on MOHO)</i>]</p>	<p>To explore the complex experience of role balance amongst working women with family responsibilities / (unknown)</p> <p>[<i>Experience of occupation</i>]</p>	<p>Multiple embedded case study (multiple), [Yin], <i>Individuals</i>, (criteria for participants)</p>	<p>Questionnaire, interviews and observation <i>Descriptive statistics and Framework Analysis technique</i> [within, and a cross-case] internally valid instruments, prolonged engagement, data and researcher triangulation, member checking, reflexivity, audit trail</p>	<p>Enhances understanding of occupation; Recommends a model to explore role balance. <i>can be compared to similar context</i></p>
<p>Stevens-Ratchford (2014), <i>AA&amp;A</i>, [USA]</p> <p>Post-positivism [<i>Occupational science, and successful ageing perspective</i>]</p>	<p>To examine model railroading as serious leisure in relation to successful aging / (what)</p> <p>[<i>Experience of occupation in relation to successful aging</i>]</p>	<p>Exploratory qualitative case study (multiple), [Stake; Yin; Creswell], <i>Individuals</i>, (Criteria for participants)</p>	<p>Quantitative data, interviews and observation <i>Qualitative analysis (codes)</i> [within, and a cross-case]</p> <p>Member checking, data triangulation</p>	<p>Enhances understanding of occupation; directions for OT <i>Not explicitly stated</i></p>
<p>Tomsone et al. (2015), <i>SJOT</i>, [Latvia]</p> <p>Not explicit [<i>The PEO model: A transactive approach to</i></p>	<p>To explore old women's experiences over time of using mobility devices / (unknown)</p> <p>[<i>Experience of occupation in context</i>]</p>	<p>Multiple case study, (multiple), [Yin; Creswell], <i>Individual</i>, (Not clear)</p>	<p>Questionnaire, interviews and observation <i>Descriptive statistics and inductive analysis</i> [within, and a cross-case]</p> <p>Data triangulation, researcher triangulation</p>	<p>Enhances understanding of interaction of context and occupation; Directions for OT and policy makers. <i>Cannot be generalised</i></p>



<i>occupational performance]</i>				
Njelesani et al. (2015), <i>FQS</i> , [Zambia]  Critical [Critical occupational approach, and occupational justice]	To explore how sport-for-development ideologies shape the participation of young people / (how)  [Contextual factors shaping occupation]	Qualitative case study design (multiple), [Stake], <i>Organizations</i> , (Bounded by time, location and function of organisation)	Interviews, observation, and documents <i>Multiple analytic techniques</i> [Unknown]  Data triangulation	Directs the focus on the assumptions and ideologies shaping occupation. <i>Not explicitly stated</i>
Cloete & Ramugondo (2015), <i>SAJOT</i> , [South Africa]  Constructivism [Framework of the family, the community and the society, and occupational science]	Explored the occupational engagement of mothers who drink excessively during pregnancy / (unknown) [Experience of occupation in context]	Instrumental case study (multiple), [Yin], <i>Individuals</i> , (Criteria for participants)	Interviews, observation, field journal, and photographs <i>Inductive thematic analysis</i> [within, and a cross-case]  Audit trail, researcher triangulation, data triangulation, member checking, reflexivity	Directs the focus on cultural, economic and socio-political factors that shape occupation. <i>Not explicitly stated</i>
Womack et al. (2016), <i>SJOT</i> , [USA]  Constructivism [Not explicit]	To explore and describe strategies used by care partners to support and maintain participation in community mobility / (unknown)  [Experience of occupation in relation to contextual factors]	Ethnographic case study (multiple), [Gomm, Hammersley & Foster], <i>Couple</i> , (Not clear)	Interviews, observation, photographs <i>Constant comparative method</i> [within, and a cross-case]  Data triangulation	Enhances understanding of occupation; Directions for OT <i>Not explicit stated</i>

CJOT = Canadian Journal of Occupational Therapy; AJOT = The American Journal of Occupational Therapy; SAJOT = South African Journal of Occupational Therapy; SJOT = Scandinavian Journal of Occupational Therapy; FQS = Forum Qualitative Sozialforschung; BJOT = British Journal of Occupational Therapy; AA&A = Activities, Adaptation & Aging; NZJOT = New Zealand Journal of Occupational Therapy; JOS = Journal of Occupational Science; OTMH = Occupational Therapy in Mental Health; ICF = International Classification of Functioning, Disability and Health ; CMOP = Canadian Model of Occupational Performance; MOHO = the Model of Human Occupation; PEO = Person-Environment-Occupation mode

### 3.2.4.1 Study demographics

The 18 included studies come from four regions: North America (N = 9), Australasia (N = 4), Europe (N = 3), and South Africa (N = 2). All the articles were published after the year 2000, and most of them after the year 2008 (N = 14). The majority were published in occupational therapy journals (N = 13) and two in the *Journal of Occupational Science*. The other studies were published in journals not specific to occupational science or therapy, but were conducted by occupational scientists and/or therapists and referred to occupational science or occupational therapy models or perspectives in their articles (Dale et al., 2003; Njelesani, Gibson, & Cameron, 2015; Stevens-Ratchford, 2014).

### 3.2.4.2 Design of study

Authors used various terms to define the type of case study they were doing. In two articles the studies were defined simply as qualitative case studies. However, the authors most commonly defined their studies based on the number of cases under study (N = 5)

(that is single or multiple/collective case studies), case selection (N = 5) (instrumental case studies), and the intent of study (N = 4) (such as interpretive or exploratory). Most studies were multiple case studies (N = 13), even though the authors may have defined their study type by something else. The paradigmatic stance of the researchers could be identified in only half of the articles, and included constructivism (N = 4), interpretivism (N = 3), critical perspective (N = 1), and post-positivism (N = 1). The prevalent case study methodologists authors referred to are Yin (N = 11) and Stake (N = 7).

#### 3.2.4.3 Study focus

Most studies were exploratory (N = 12). Seven of the articles did not state their research questions, and the remainder asked “how” and “what” questions; except one that asked a “why” question. Eleven studies focused on occupation in a context, for example disabled children’s experiences of out-of-school activities in various settings (Harding et al., 2009). In three of the articles, studies focused on occupation in relation to wellbeing, such as healthy aging or quality of life (Stevens-Ratchford, 2014; Wood et al., 2009). Two studies aimed attention at how trauma, or more precisely cumulative trauma or stroke, shapes occupation (Dale et al., 2003; George et al., 2001). One study focused solely on experience of role balance (Evans et al., 2014), and another one explored how sport participation of young people is shaped by certain contextual factors, using a critical perspective (Njelesani, 2015).

Regarding how the findings of the studies may be applied to occupational science or therapy, most authors concluded with directions for occupational therapy practice (N = 10) but, overall, they enhanced understanding of occupation in some way. Authors commonly stated that the findings may be transferred or compared to similar contexts (N = 5), and were not generalisable (N = 9).

#### 3.2.4.4 The bounded case(s)

In some instances, it was not clear what the case was (N = 3), or boundaries of the cases were not identifiable (N = 5). In the articles where the cases were identifiable, or defined by the authors, the most common cases were individuals (N = 11). Other cases were couples (N = 2), a group (N = 1), and an organisation (N = 1). The prevailing boundaries that could be identified were based on the inclusion criteria for individual participants (N = 11), such as related to health status, age, living situation, gender, education, and/or experience. Two studies had clear boundaries for their case, other than inclusion criteria for their participants. Njelesani and colleagues (2015) bounded their case by ideology and function of an organisation, time, and location; and Basiletti and Townsend (2012) specified working group in a certain location.

### 3.2.4.5 Methods

Eleven studies used multiple methods to collect data, four used two methods, and three used only one method. The dominant data collection methods were interviews (N = 18) and observations (N = 13). Other methods were questionnaire/survey/quantitative data (N = 6), documents/case notes/field journal (N = 5), photographs (N = 4), and group discussions (N = 1). Six studies used mixed methods, one used only quantitative methods, but the majority were qualitative (N = 11).

Various terms were used for data analysis methods applied in the studies. However, the most common methods seem to be descriptive statistics for the quantitative data, and inductive analysis for the qualitative data such as coding and content analysis.

When reviewing strategies that researchers used to enhance quality in their case studies, the most common ones were: data triangulation (N = 13), researcher triangulation (N = 9) and member checking (N = 9). In two studies, it was not clear what kind of strategies were used for quality purposes, if any. Two studies that were recorded in this review as not using multiple methods, did state they used triangulation, which may be explained by using both multiple interviews and observations in more than one location.

### 3.3 Discussion

Use of case study methodology is increasing internationally to explore and understand occupation. If applied with rigour, case study methodology is a useful approach to gain a deep understanding of a phenomena in its real-life context (Merriam, 1997; Simons, 2009; Stake, 1995; Yin, 2014). Common occupational science and therapy theories suggest that occupation cannot be isolated from its context ( Dickie, Cutchin & Humphry, 2006; Kielhofner, 2008; Law, Cooper, Strong, & Stewart, 1996; Townsend & Polatajko, 2007; Wilcock & Hocking, 2015), and therefore, the research approach can be considered valuable to understand occupation. Following are suggestions on further potential for use of case study methodology for the study of occupation.

The methodology is flexible and allows for creativity; the findings of the review support this principle. For example, the researchers presented different case study types and used various perspectives and data analysis methods. This flexibility and creativity are valuable when designing a study to look at the complex phenomenon of occupation. They provide for the use of various theoretical perspectives, paradigms, and methods for data collection and analysis. This variety enables acquisition of a deep understanding of occupation, through inclusion of multiple perspectives; incorporating the viewpoints of relevant stakeholders and situating the phenomena of interest within a context understood, in part, through influential documents and other materials.

However, similar to what has been identified by Hyett et al. (2014), it was striking how many of the studies lacked the essential characteristics of case study research, that is description of the cases and their boundaries, use of multiple sources of data, and explicit information about the research process in the output. Furthermore, the relevancy screening process assigned 91 articles a low score because they did not refer to any case study references, despite stating they were doing case study research. These findings indicate some confusion about what case study research is, and lack of consistency in how it is applied.

The limited way that case study methodology has been used to study occupation was notable in our findings. Although the methodology fits well when looking at an individual as the case under study, as is prevalent in the study of occupation, it offers many other opportunities to study occupation as it relates to groups, communities, policies, processes, systems and more (Simons, 2009; Stake, 1995; Yin, 2014). Indeed, the theoretical perspectives used in most of the included studies take into account the interaction between a person, occupation and context, and their main focus was on occupation in its context. Thus, the cases could be defined as occupation in its context, or even as contextual factors shaping occupation, rather than as individuals. If the intention is to understand the experience of individuals, then they may form the cases. Including occupation and the context within the definition of the case could better emphasise the

key concept under study and lead to application of methods that capture the complexity of occupation, particularly how it is shaped by context in transaction with the person.

Boundaries of many of the cases were difficult to identify in the articles reviewed. Those cases where boundaries were identified were predominantly individuals, and the recruitment criteria were considered their boundaries. This limited application of the methodology restricts its usefulness for the understanding of occupation in context, which can be further expanded through a broader definition of the case and its boundaries.

Defining and bounding the case more broadly, including enough context to understand it, can help to gain greater understanding of the complexity of occupation. For example, the cases may be bounded by location, time, or other contextual limiters (at micro or macro level), specifics about occupation under study, as well as characteristics of a group, such as age span, gender, health status, functional level, profession, and education. Thus, a hypothetical bounded case could be ‘Sport participation of teenage girls with mobility impairments who are registered in a specific youth program at a certain time’ or ‘Specific services that can support leisure occupation of elderly people living in a specific neighbourhood’.

In addition to thinking differently about what a case can be, defining it as something other than an individual may help researchers to think of different sources for data. As noted earlier, one of the aspects that is critical for case study research is to look at a case



from different perspectives and use multiple sources of data (Merriam, 1997; Simons, 2009; Stake, 1995; Yin, 2014). Thus, it was surprising that seven of the studies reviewed did not comply with this criterion; particularly, as it is important to gather information about the individuals, the occupation and the context to understand occupation.

Researchers are encouraged to consider the various ways of collecting data for each case under analysis, as it helps to gain greater depth of understanding, and is important for data triangulation which helps validate or reinforce findings of case study research (Hancock & Algozzine, 2011; Merriam, 1997; Simons, 2009; Stake, 1995; Yin, 2014) and for crystallisation, to gain more complex and in-depth findings (Tracy, 2010).

Considering the above-mentioned hypothetical case of teenage girls, there are many possible data sources, such as observations, interviews, focus group discussions and/or surveys with different stakeholders, documents that relate to the program, policies, geographical information, and so forth. Additionally, data sources can relate to both micro and macro level contextual factors, such as assessment of the physical environment (micro level), or policies that shape the physical environment (macro level).

One of the challenges when reporting case study research is adherence to word limits in academic journals while simultaneously presenting thick description of the case in its context, and being explicit about the whole research process (Hancock & Algozzine, 2011; Simons, 2009; Swanborn, 2010). Such limitations may have prevented authors of the reviewed articles from including relevant details. Alternative means of reporting case

studies might be considered, such as to publish a sequence of articles that present a study in phases, concluding with a synthesis of the overall case.

### 3.3.1 Limitations

This review was limited to only one type of report, that is research articles in academic journals. Because case studies are challenging to report in regular journal articles, more case studies within the field might have been found in PhD dissertations or books. A more in-depth understanding of the use of case study methodology in the field might also have been gained by review of these types of sources.

## 3.4 Conclusion

Case study methodology is increasingly used for the study of occupation, and offers a creative and flexible way to gain better understanding of a case, such as occupation, in its context. This methodology aligns with the understanding that occupation is a phenomenon situated in context, and we see this methodology as useful to understand the complexities of occupation in different settings, from various perspectives.

Recommendations were provided on the essential features of case study to advance the appropriate use of case study methodology for studying occupation. These features focus on the importance of defining the bounded case in its context, using multiple sources of data, and ensuring the output is transparent. Occupational scientists are encouraged to

familiarise themselves with case study methodology and the various ways it may be used in their future research.

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## Chapter 4

### 4 The approach to this study

My approach to this study is case study methodology as described in chapter three. Since this work is presented in an integrated manuscript style, and the methodology used has been presented in chapter three (which is a published article), this chapter serves to provide information on how the approach was used for this particular study.

#### 4.1 Choice of methodology

Case study methodology is useful to apply multiple perspectives to study a particular case in its context to gain deeper understanding of it (Merriam, 1997; Simons, 2009; Stake, 1995; Yin, 2014). Based on the findings of the literature review presented in chapter two, the broad overall objective of my study was to enhance understanding of how services, systems and policies shape community mobility for people with mobility impairments. Case study methodology suits well to look at the complex interplay between occupation, people and the context (Jónasdóttir, Hand, Misener & Polgar, 2018). Thus, it fits well to look at the complex interplay between community mobility, the services, systems and policy context in which it occurs, and the intended recipients of those contextual factors. Furthermore, case study methodology fits well when the focus is on complex social and political phenomenon and contemporary events in the society, and to inform practice

(Yin, 2014; Simons, 2009). When writing about strengths of case study research, Simons (2009) claims that the approach “enables the experience and complexity of programmes and policies to be studied in depth and interpreted in the precise socio-political context in which...[they] are enacted” (p.23). This complexity of the Icelandic policy context can be seen further below in this chapter. Policy context is a dynamic and constantly shifting domain, which requires the flexibility of the case study approach of use of various methods that are fitting to understand the case at any given time (Simons, 2009).

Before I go into details describing the case study I conducted, I will provide a short recap of the essential characteristics of case study methodology as described in chapter three (Jónasdóttir, Hand, Misener & Polgar, 2018). First, there is a tight connection between the case and the context in which it is situated and thus there needs to be a clear description of both the case and its context. Second, in case study research it is essential to use multiple sources of data. And third, all decision and actions should be made explicit for the readers, such as regarding paradigmatic stance, research questions, case selection and methods used for the study.

Thus, below in this chapter I outline my paradigmatic perspective as a researcher, followed by an introduction of the research questions addressed in this study. Next, the bounded case will be defined, and the study site selection explained. After that the policy context in Iceland related to the study topic is introduced. In the latter part of this chapter



the methods for data selection, collection and analysis for each study phase are presented. Lastly, quality considerations for this case study is addressed.

## 4.2 Paradigmatic stance

Because of the flexibility of case study methodology to accommodate various paradigmatic perspectives as identified in chapter three, the practice of reflexivity or situating the researcher in the research process is especially important (Merriam, 1997; Simons, 2009). Furthermore, as this case study is qualitative in nature, it is essential to locate myself as a researcher and explain my paradigmatic stance (Crotty, 1998). The paradigmatic stance shapes the way the researcher conducts research, the choices of methods applied etc. (Creswell; 2014). Thus, I will now explain the perspective that guided me in this research project.

I believe that there is no one right way or one paradigm that suits best to conduct research. Rather, the paradigmatic stance of the researcher depends on the purpose of the research being conducted. For that reason, my ideas about research align well with a pragmatic perspective where the focus is on pluralistic approaches to gain understanding of the research problem and what works to solve the research problem. A pragmatic worldview fits also well with case study methodology as it embraces the importance of using pluralistic ways to gather information about the research topic (Creswell, 2014).

Even though mixed methods are often applied within pragmatism studies, in this particular study the research problem addressed called for qualitative methods as the objective was to enhance understanding of a case, on a topic that little is known about (Creswell, 2014). Thus, a constructivist perspective was also adopted which assumes that there is no one truth, but multiple constructed realities. This perspective is grounded in a relativist ontological position, which emphasises that those realities are created by individuals as they interact with a context (Guba & Lincoln, 1994). According to Crotty (1998) a constructivist view is that “all knowledge, and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context” (p. 42). Thus, people can have different views on the same circumstances, depending on their experiences.

Epistemologically, this paradigm assumes a subjectivist perspective, emphasising that the findings are co-constructed between the researcher and participants, and are thus not discovered (Crotty, 1998; Guba & Lincoln, 1994). Subjectivity has been identified as “an essential element of understanding” (Stake, 1995, p. 45). Simons similarly states that “subjective data are an integral part of the case. It is through analysis and interpretation of how people think, feel and act that many of the insights and understanding of the case are gained. It acknowledges that you are the main instrument in data gathering, interpretation and reporting” (p.4).

### 4.3 Research questions

This case study was divided into two phases. The main research question for phase one was: *How can services, systems and policies restrict or support community mobility for people with mobility impairments?* A sub-question for this phase was: *What is the relationship among these infrastructure factors, community mobility, and occupation?*

The research questions for phase two got narrower as I got to know the case and its context better. Based on the findings from phase one, the questions for phase two were: *How do legal texts, policies, and other public documents from national and local authorities depict transportation services for disabled people in the town of Akureyri, Iceland?* And *How do legal texts, policies, and other public documents from national and local authorities depict services affecting physical accessibility in the town of Akureyri, Iceland?*

### 4.4 The bounded case

The broad definition of the bounded case in phase one was: the implementation of any Icelandic services, systems, and policies that restrict or support community mobility for people with mobility impairments in Akureyri.

In the second phase of the research process, when better understanding of the case had been gained, the boundaries were redefined by certain service areas identified by service users and service providers. Thus, the case in phase two was: Transportation and accessibility services, systems and policies that restrict or support community mobility for people with mobility impairments in Akureyri.

When decisions regarding boundaries were made, discussion occurred regarding whether the case should be bounded by time, such as by policy documents that were valid during the year of 2014 while the focus group discussions took place. However, since this research is within the flux policy field, the research would not be relevant and not pragmatic if the newest changes in policy documents were not incorporated. In this instance, the case is thus bounded by a geographical location, that is the town of Akureyri, and by characteristic of a certain group of people, that is adults with mobility impairments.

#### 4.4.1 Study site selection

This study revolves around people with mobility impairments in a town called Akureyri, in Iceland. This town is located in the northern part of the country, on a mountainside and has multiple slopes and hills. Since the town is situated in Iceland, an island in the north Atlantic, it is just south of the arctic circle. Therefore, the summers are bright and short, while the winters are long and dark, often with very harsh weather.

The following reasons affected my choice to bound the case to this location. First, I have a connection to this town. I grew up close to it and moved there as a young adult to study occupational therapy. Furthermore, during my studies and after graduation I worked in this town with disabled people, both in their homes and in the society. Thus, it seemed rational to bound the case by a geographical location which I was familiar with and had experience of living and working in.

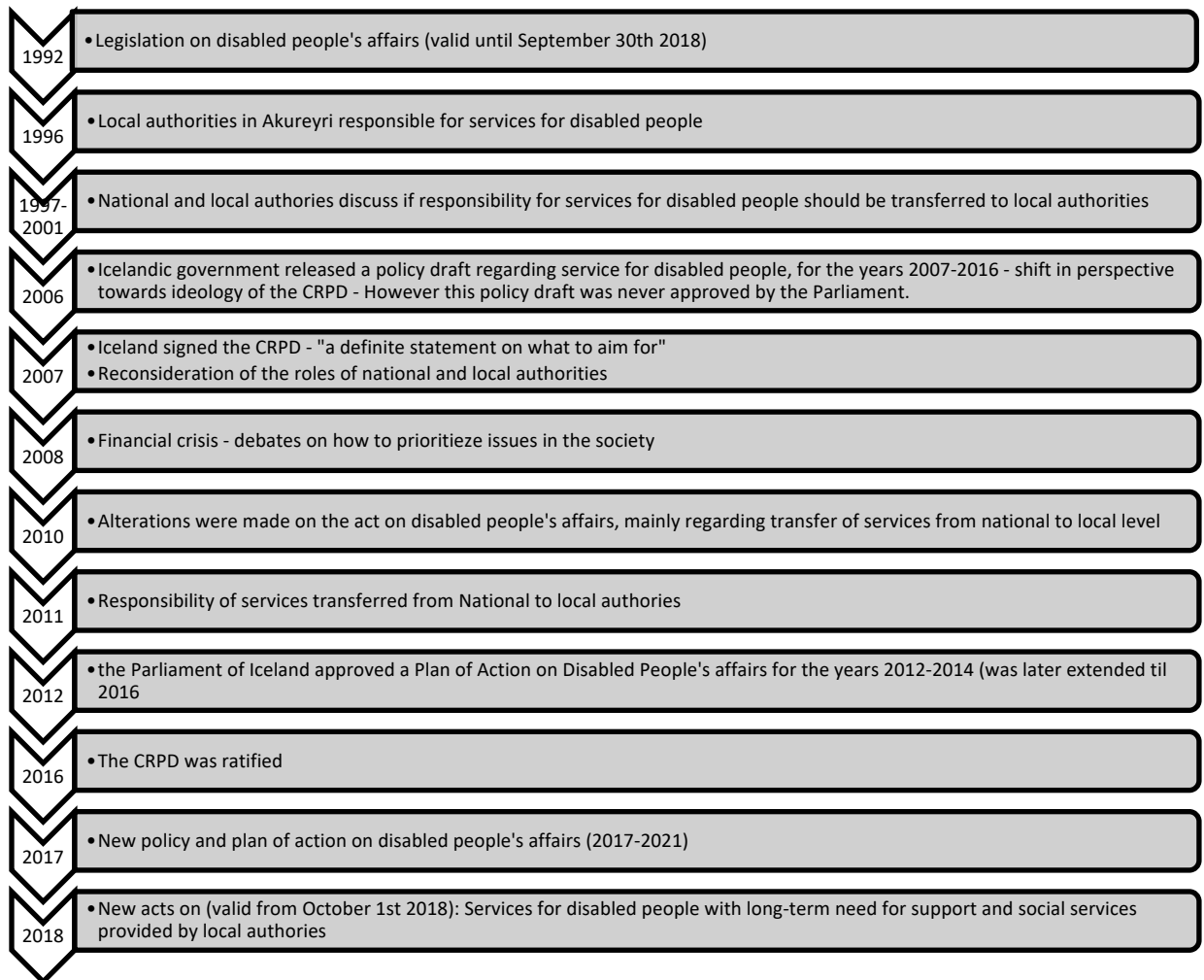
Second, no similar studies have been conducted in Northern Iceland. Akureyri has a population of about 18,000 people (Statistic Iceland, 2016) and is the largest town in Northern Iceland. According to Statistics Iceland (2014), 15,4% of adult disabled people, who get services from local authorities, have mobility impairments, and thus, about 70 individuals have mobility impairment in the town of Akureyri.

#### 4.4.2 The policy context

In Iceland, the Ministry of Social Affairs (called Ministry of Welfare prior to January 2019) is in charge of all matters having to do with disabled people's affairs. The Minister of Social Affairs and Children (called Minister of Social Affairs and Equality prior to January 2019) is responsible for all policy formulation in the field. The policy has to be formulated in cooperation with the Association of Icelandic local authorities, and organized interest groups of disabled people are to be consulted. The Minister of Social Affairs and Children is further responsible for monitoring the implementation of the

legislation on disabled people's affairs in Iceland (Act no. 59/1992; Act no. 38/2018). Significant changes have resulted in disabled people's affairs in Iceland, including most recently the ratification of the United Nations' Convention on the Rights of Persons with Disabilities (CRPD), which indicates authorities consent to being bounded to this treaty, and commitment for arrangements to implement the obligations of the CRPD. Changes have been made in the legal aspect with the intention to fulfill the requirement of the CRPD. However, there are certain events from the last 15-20 years that can be argued to have fundamentally influenced the policy on disabled people's affairs in Iceland. Those events are presented below and listed in a chronological order in Figure 5.

**Figure 5: Events that have influenced the policy in the disability field in Iceland**



The CRPD was adopted at the UN General Assembly in the year 2006 (United Nations Enable, n.d.). The same year the Icelandic government released a policy draft regarding services for disabled people in Iceland for the years 2007-2016 (Ministry of Welfare, 2006), but this draft was never approved by the Parliament. Still, the draft reveals some shift in perspective towards the social perspective of the CRPD, where contextual factors play a major role in shaping disability, turning the focus less on the individuals and their impairments.

The Icelandic government signed the CRPD in the year 2007. The former Minister of Welfare stated, in his speech at a symposium regarding the CRPD, that “by signing the CRPD the government has issued a definitive statement on what to aim for regarding the rights of people with disabilities in most or all sector of society” (Hannesson, 2012). The CRPD was then finally ratified in 2016 (Government offices of Iceland, n.d.). Part of the reason why the ratification took so long time seems to be that the government was reviewing current legislation and figuring out a way to change it in order to fulfill the requirements of the CRPD. Another aspect that probably did not support faster transition was the financial crisis that threatened the economy of Iceland and almost lead to the bankruptcy of the nation in 2008 (The Telegraph, 2008). Following, financial resources were unconventionally limited and there was a constant debate on how to administer these resources and prioritize issues in the society. In addition, there have been frequent changes of ministers which slowed the process down.



Finally, on April 26th, 2018, the Icelandic parliament approved a new act regarding services for disabled people with long-term needs for support, which will replace the act on disabled people's affairs which has been valid since the year 1992, with some small amendments done throughout the years (Act no. 38/2018; Act no. 59/1992). The new act represents a big milestone in the policy regarding service for disabled people in Iceland, as long-awaited changes are incorporated that are more in line with the principles of the CRPD, including both independent living ideology and social perspective on disability, as well as improvement of service forms offered, such as legalising user controlled personal assistant services (Act no. 38/2018). At the same time, amendment of the act on social services provided by local authorities was accepted, which reflects similar changes in ideology. These two acts have to be synchronised as they support each other (Althingi, 2016).

During those formative years in the field, the Parliament of Iceland has approved policies and plans of actions which are based mainly on articles from the CRPD. Those plans serve as a framework and can guide local authorities regarding some service areas they are to deliver (Ministry of the Interior, 2013; Resolution no. 16/146, 2017; Resolution no. 43/140, 2012). The first plan approved by the Parliament was from 2012-2014, but was later extended until 2016 (Resolution no. 43/140, 2012; Ministry of Welfare, 2016). The newest policy and plan of action was approved in 2017 and is valid from the year 2017-2021 (Resolution no. 16/146, 2017). The old plan, and the impact assessment of that plan,

have been criticized for lack of progress towards many of the sub-objectives they were working towards. Furthermore, it has been pointed out that there is a need for more holistic policy formulation in the field (University of Iceland – the Centre for Disability Studies, 2017).

#### 4.4.3 Responsibility of service implementation

As part of a pilot project of transferring responsibility of service for disabled people from national to local level, local authorities in Akureyri have been responsible for all services in their area since 1996 (PricewaterhouseCoopers, 2000, Eyjafjordur, 2014). Despite all efforts to transfer this responsibility of services nationally in the years 1997-2001, no agreement was reached at that time between local and national authorities, mainly because of disagreements regarding financial issues (Association of local authorities, n.d.). The decision to reconsider the roles of national and local authorities regarding services for disabled people was made in the year 2007 (Association of local authorities, n.d.). and it seems like this transfer of responsibility of service became one of the implementation strategies to working towards the requirements of the CRPD. This decision seems to be influenced by the CRPD, changing the focus of authorities towards the responsibility of the society to support disabled people's participation in the society. An agreement was reached and signed by both parties in November 2010, and the transfer took effect in January 2011 nationally (Ministry of Welfare, n.d.). All services

that people were entitled to according to the Act on disabled people's affairs (1992) were hence the responsibility of local authorities.

The main objective of the transfer nationally was to ensure that professional and financial responsibility would be on one administrative level and support integration of services and thus strengthen the social services for residents (Ministry of Welfare, 2015). On the local level in Akureyri, the goal has always been to integrate services for disabled people and other social services and provide services according to the needs of individual users. Additionally, their stated emphasis in that service area is integration, teamwork and simplification of services for the users so they can get appropriate support for participation in society. Furthermore, even though the services in Akureyri have been considered exemplary for other service areas, local authorities in Akureyri have stated that they always aim to improve and develop the services according to new standards, knowledge and needs (Eyjafjordur, 2014).

## 4.5 Methods

Data collection methods used in this study were qualitative in nature. According to case study methodologists, a case has to be looked at from various perspectives, which can be done by using multiple methods (Merriam, 1997; Simons, 2009; Stake, 1995; Yin, 2014). Thus, in this study focus groups were conducted that involved participants representing

different groups, as well as analysis of public documents from multiple websites. The findings from phase one helped to guide data collection in phase two.

#### 4.5.1 Methods for phase one

The research that informed chapter five is based on focus group interviews with people with mobility impairments in the town of Akureyri (service users) and people who have long experience of providing services for disabled people in that same area (service providers). Ethics approvals were obtained from both the National ethics board of Iceland (certificate no. 14-089 CM; see Appendix C) and the Western University research ethics board (certificate no. 105537; see Appendices A and B) before any recruitment or data collection occurred.

##### 4.5.1.1 Participants and recruitment

An occupational therapist working for the Association of Disabled People in Akureyri agreed (Appendix X) to act as a gatekeeper and to help identify service users to potentially participate in the study. She provided service users with an information letter (Appendix D) about the study, and upon their permission (Appendix Z), she sent me the service user's contact information.

Purposive sampling was used for recruitment. The criteria for participants in the service users' groups was that they were 18 years or older and had at least 18 months experience

of a daily mobility device use, such as manual wheelchairs, powered wheelchairs and/or walkers. They were also living independently in the community of Akureyri, meaning they were not living in any institution, such as long-term care or nursing facilities. Furthermore, they did regularly (at least twice a week) go out to some community venues in that area and were able to actively participate in a focus group interview. The aim was to get some variation regarding age, gender and type of mobility devices used.

A person with long experience of working in the disability service sector in the area helped identify potential participants for the service providers' group (Appendix Y). This person provided me with a list of potential participants and their emails. Those potential participants were sent an email with an information letter about the study (Appendices F and H). They then contacted me if they were interested in participating.

The service providers had to have at least two years' experience of planning and/or providing services for disabled people in the town of Akureyri. Additionally, they had to have experience of direct communication with disabled people in their work. Such interactions arose from when service providers were assisting disabled people in their daily lives, in their homes or out in the community, or because they served as consultants for disabled people in the area.

For both groups, I called the individuals who had shown interest in participating and answered any questions they had regarding the study. An informed written consent (Appendix J) was obtained at the time the focus group discussion occurred, prior to collecting the data.

The reason a gatekeeper was used for the recruitment strategy of service users is because I had been working with disabled people in this community before, which could make potential participants feel pressure to participate. The gatekeeper strategy created a distance between me and the potential participants, which limited any such pressure. However, even though having this experience of working with disabled people in Akureyri before, I did not have any relationship with the actual participants prior to conducting this research.

#### 4.5.1.2 Data collection for phase one

Two focus groups were conducted with service users, and one with service providers. The discussion took place in the facilities of the University of Akureyri in December 2014, and each interview lasted between one and two hours. I was the moderator for the focus group interviews. No assistant was needed since the groups were small.

Participants were asked open-ended questions regarding how services, systems, and policies shape community mobility of people with mobility impairments. Participants

were for example asked where people with mobility impairments want and need to go, how they go there and what places they cannot go to. They were also asked about barriers to community mobility and how services, systems and policies could facilitate community mobility for people with mobility impairments. The participants were asked open-ended questions, so they had opportunities to share their views on the situation of people with mobility impairments, with the aim of gaining understanding of the context they are situated within. The introduction and question guides were developed with the intention to evoke conversation and create a natural atmosphere. I also tried to avoid any jargon and used words that are common in everyday conversation. The guides were furthermore developed in Icelandic, participants' first language, and only translated to English for the purpose obtaining approval from Western University research ethics board (See appendices N, O, R and S).

Participants were also asked to answer a short questionnaire that gave additional information that added insight into the composition of the group and the experiences of the participants (see appendices T, U V and W). Main characteristics of participants can be seen in chapter five, table 11. The demographic information gathered in the research was only used to report aggregate data and was not linked back to any individuals because the participant recruitment pool and community are so small.

The focus group discussions were digitally audio recorded for transcription, which I did within two weeks after the group discussion took place. After typing up the transcripts verbatim in Icelandic, I translated them into English for my supervisor at Western University to review, as she does not read or understand Icelandic. Instead of verbatim translation, the focus was on conveying the meaning of the text. If the text had been translated word-for-word, it might have obscured the meaning. To determine if both language versions of the transcripts conveyed similar information, an Icelandic member of the advisory committee, who is fluent in both languages, read and compared both versions.

#### 4.5.1.3 Data analysis for phase one

An inductive content analysis was used to analyse the data from focus group interviews (Elo & Kyngäs, 2008; Hsieh, 2005). This analysis was informed by the formal data-structure analysis approach (FDSA), which is an hermeneutic interpretive approach, where the researchers can reflect on own experiences during the interpretation (Borell, Nygård, Asaba, Gustavsson & Hemmingsson, 2012; Gustavsson, 1996), and aligns well with a constructivist perspective (Creswell, 2014). Additionally, an occupational perspective was used when interpreting the data. Njelesani, Tang, Jonsson & Polatajko (2014) describe occupational perspective as “looking at or thinking about human doing” (p. 233). During our analysis and interpretation, we thought about the connection



between occupation and community mobility by considering how services, systems and policies affects people's community mobility and by that also affect opportunities people have to be involved in occupations that are meaningful to them.

The transcripts were coded independently, the Icelandic version by me, and the English version by my supervisor. The data analysis software Atlas.ti (version 1.0.30) was used when manually coding and recoding the data, after reviewing it multiple times. We then came together and compared and discussed our coding. After that all potential and reasonable interpretation of the data were formulated and organized into themes that shared similar ideas. These themes were then tested against the original data, as suggested by Gustavsson (1996). This was done to confirm that the researcher's interpretations were supported by the data. Additionally, the Icelandic member of the advisory committee reviewed the codes and themes that had been developed and verified the findings, the interpretations were true to the data, and no new themes should be developed. After this verification, the research team discussed the main aspects of the quotes we used for our analysis to label the themes for the findings.

After the analysis of data from the focus groups, reflections on the researchers' interpretations were sought from participants who had agreed to be contacted again for this purpose. Responses were received from three service providers, who confirmed the findings that had emerged. It is unknown why service users did not provide feedback, but

it may relate to time elapsed from when the focus group discussion took place, as more than a year passed before feedback was sought.

#### **4.5.2 Data collection and analysis methods for phase two**

Public documents collected from official websites were reviewed for phase two. The data collection and analysis of these public documents took place from October 2017 – June 2018. The search for relevant documents was based on findings from the first phase, which identified services affecting accessibility and transportation as the main service areas under consideration. Another service area was identified as important to support people's community mobility, that is personal assistant services. However, after thorough consideration and discussion within the research team, the focus of this phase was on two of the service areas, that is transportation and physical accessibility. The rationale behind this decision is the following: (1) Both of these service areas are aimed at improving the opportunities people have to move around in their communities, which is the scope of this dissertation. In contrast, the personal assistant services cover broader variety of users' needs, or all aspects of their lives; (2) Recent changes in legislation in Iceland have legalised user-controlled personal assistant services in the country. However, this recent change in legislation, which has not been followed up yet with appropriate regulations and guidelines, makes this service area in an instable and flux stage, where decisions have not been made regarding its implementation.

The websites that were searched for documents are official websites of both national and local authorities. The following websites were searched manually:

- The Parliament of Iceland ([althingi.is](http://althingi.is))
- The Althing ombudsman ([umbodsmadur.is](http://umbodsmadur.is))
- The Icelandic government offices ([stjornarrad.is](http://stjornarrad.is))
- The Icelandic Construction Authority ([mannvirkjarstofnun.is](http://mannvirkjarstofnun.is))
- The Association of local authorities ([samband.is](http://samband.is))
- The local authorities in Akureyri ([akureyri.is](http://akureyri.is) and [visitakureyri.is](http://visitakureyri.is))

Those websites were manually searched for documents with information that relate to transportation services, as well as physical accessibility. For the purpose of reviewing documents on transportation, both the aspect of public transportation, as well as accessible transit services specifically offered to disabled people (hereafter called transit services) were explored. Public transportation may be considered as any scheduled means of passenger transportation that are available for the public. However, for the purpose of this paper, public transportation refers only to fixed route buses available for the public, either for fee or free of charge. No trains or subways are in Iceland.

The documents included in this analysis included acts, resolution, policies and plans of actions, official guidelines, regulations, research reports, minutes from meetings, application forms and checklists, as well as general information about certain services

posted directly on those websites. Some information found in the documents indicated additional documents, that would be helpful for this phase. In those cases, emails were sent to local authorities in Akureyri to request those specific documents (in total 3). These requests resulted in access to one research report.

The criteria for data inclusion were official information that provided information on policies regarding 1) physical accessibility, 2) public transportation or transit services for disabled people, or 3) the implementation of such services. Information about data sources used for this phase are provided in Table 9 (in total 42). Many documents that did discuss these service areas were excluded because they did not provide any new information as they simply referred to other documents that were already included such as legal texts, policies, etc.

**Table 9: Data sources used for policy review**

Citation in text	What is it	Found on which website
Act no. 28/2017	Lög um farþegaflutninga og farmflutninga á landi [Act on onshore passenger transportation and freight transport]	Althingi.is
Act no. 59/1992	Lög um málefni fatlaðs fólks [Act on disabled people's affairs]	Althingi.is
Act no. 37/2018	Lög um breytingu á lögum um félagsþjónustu sveitarfélaga, nr. 40/1991, með síðari breytingum (innleiðing sammings Sameinuðu þjóðanna um réttindi fatlaðs fólks, stjórnsýsla og húsnæðismál [Act on amendment on the act on social services provided by local authorities (integration of CRPD, administration and housing affairs)].	Althingi.is

Resolution no. 16/146, 2017	Þingsályktun um stefnu og framkvæmdaáætlun í málefnum fatlaðs fólks fyrir árin 2017-2021 [Resolution on a policy and plan of action on disabled people's affairs for the years 2017-2021]	Althingi.is
Resolution no. 43/140, 2012	Þingsályktun um framkvæmdaáætlun í málefnum fatlaðs fólks til ársins 2014 [Resolution on a plan of action on disabled people's affairs to the year 2014]	Althingi.is
Ministry of Welfare, 2016	Framkvæmdaáætlun í málefnum fatlaðs fólks 2012-2014. Stöðu- og árangursmat [Plan of action on disabled people's affairs 2012-2014. Status and impact assessment]	Stjornarradid.is
Regulation no. 475/2017	Reglugerð um gildistöku reglugerðar Evrópuþingsins og ráðsins (ESB) nr. 181/2011 frá 16. febrúar 2011 um réttindi farþega í hópþingum og um breytingu á reglugerð (EB) nr. 2006/2004. [Regulation on ratification of the European parliament and union regulation no. 181/2011, from February 16th, 2011 regarding the rights of passengers in buses and amendment on regulation no. 2006/2004]	Stjornarradid.is
Regulation no. 181/2011	Reglugerð Evrópuþingsins og ráðsins (ESB) nr. 181/2011 [European parliament and union regulation no. 181/2011]	Stjornarradid.is
Sjálfsbjörg, 2017	Viðbótarumsögn um frumvarp til laga um Farþegaflutninga og farmflutninga lagt fyrir Alþingi á 146. löggjafarþingi 2016-2017. Þskj. 187 - 128. Mál. [Sjálfsbjörg – Association of people with mobility impairments – additional comments on resolution regarding onshore passenger transportation and freight transport, on 146. Congress in the Parliament 2016-2017. Parliamentary document no. 187 - Case 128]	Althingi.is
Act no. 120/2012	Lög um Vegagerðina, framkvæmdastofnun samgöngumála [Act about the Icelandic road and coastal administration]	Althingi.is
Town of Akureyri, 2018	Strætó [Buses]	Akureyri.is
Akureyrarstoða, 2018	Leiðabók SVA frá 1. febrúar 2018 – tímatöflur [Routes guide SVA from February 1st, 2018 – timetable]	Visitakureyri.is

Town of Akureyri, 2016a	Samstarfsnefnd um ferlimál fatlaðra, 1. Fundur, 7. mars 2016 [Joint committee on transportation for disabled, 1st meeting, March 7th, 2016]	Akureyri.is
Town of Akureyri, n.d.c	Úttekt aðgengismála að strætisvögnum og SVA [Assessment of accessibility to buses and bus stops]	Through email request
Town of Akureyri, 2017b	Umhverfis- og samgöngustefna [Environmental- and transport policy]	Akureyri.is
Ministry of Welfare, 2012	Leiðbeinandi reglur fyrir sveitarfélög um ferðaþjónustu fyrir fatlað fólk, samkvæmt lögum nr. 59/1992, um málefni fatlasð fólks, með síðari breytingum [Guidelines for local authorities regarding transportation service for disabled people, based on Act. no. 59/1992, on disabled people's affairs, with last amendments]	Stjornarradid.is
Town of Akureyri, 2010	Reglur um akstursþjónustu á Akureyri [Policy on transportation service in Akureyri]	Akureyri.is
Town of Akureyri, 2016b	Drög að Velferðarstefnu Akureyrar 2017-2021 [Draft of a welfare policy for Akureyri 2017-2021]	Akureyri.is
Town of Akureyri, 2012a	Samstarfsnefnd um ferlimál fatlaðra, 1. Fundur, 10. september 2012 [Joint committee on transportation for disabled, 1st meeting, September 10th, 2012]	Akureyri.is
Town of Akureyri, 2013b	Ferliþjónusta Akureyrar - Könnun um ánægju notenda, 6-67 ára [Transportation service of Akureyri – Survey on users' satisfaction, 6-67 years old]	Akureyri.is
Town of Akureyri, 2017a	Ársskýrsla Akureyrarbæjar 2016 [Annual report for the town of Akureyri 2016]	Akureyri.is
Town of Akureyri, 2013a	Ársskýrsla Akureyrarbæjar 2012 [Annual report for the town of Akureyri 2012]	Akureyri.is

Town of Akureyri, 2015	Ársskýrsla Akureyrarbæjar 2014 [Annual report for the town of Akureyri 2014]	Akureyri.is
Town of Akureyri, 2014	Ársskýrsla Akureyrarbæjar 2013[Annual report for the town of Akureyri 2013]	Akureyri.is
Parliament, 2018	Öll erindi í 27. máli: félagsþjónusta sveitarfélaga [All comments on amendments on the act on social services provided by local authorities]	Althingi.is
Welfare committee, 2018	Nefndarálit um frumvarp til laga um þjónustu við fatlað fólk með miklar stuðningsþarfir og frumvarp til laga um breytingu á lögum um félagsþjónustu sveitarfélaga [Committee report on resolution regarding act on services for disabled people with extensive need for support, and resolution regarding amendments on the act on social services provided by local authorities]	Althingi.is
SVA, 2016	Leið 6: Síðuhverfi-Naustahverfi [Route 6: Síðuhverfi-Naustahverfi [Route 6 - Map of a bus route in Akureyri]	Visitakureyri.is
Town of Akureyri – department of residence, 2017, p.1	Umsókn um akstursþjónustu [Application for transit service]	Akureyri.is
Althing ombudsman, file no.9160/2016	Álit og bréf - Mál nr. 9160/2016 [Comment on case no. 9160/2016]	Umbodsmadur.is
Act no. 160/2010	Lög um Mannvirki [Building code act]	Althingi.is
Regulation no. 112/2012	Byggingarreglugerð [Building code regulation]	Mannvirkjastofnun.is
Iceland construction	Leiðbeiningar við byggingarreglugerð [Guidelines for the building code regulation]	Mannvirkjastofnun.is

authority, n.d.		
Iceland construction authority, 2014	Verklagsregla [Procedure policy]	Mannvirkjastofn un.is
Iceland construction authority, 2018a	skoðunarlisti öryggisúttektar [Inspection list for safety inspection]	Mannvirkjastofn un.is
Iceland construction authority, 2018b	skoðunarlisti lokaúttektar [Inspection list for final inspection]	Mannvirkjastofn unis
Iceland construction authority, 2018c	skoðunarlisti – hönnunar [Inspection list for design inspection]	Mannvirkjastofn un.is
Town of Akureyri, 2012b	Samþykkt fyrir samstarfsnefnd um ferlimál fatlaðra [Agreement regarding joint committee on mobility issues for disabled people]	Akureyri.is
Town of Akureyri, n.d.a	Ferlinefndar fundargerðir [Accessibility committee - Minutes from meetings]	Akureyri.is
Town of Akureyri, 2018c	Snjómokstur og hálfuvarnir [Snow clearing and prevention of icy road conditions]	Akureyri.is
Town of Akureyri, 2018b	Aðalskipulag Akureyrar 2018-2030 [Main land use plan for Akureyri 2018-2030]	Akureyri.is
University of Akureyri research centre, 2017	Viðhorf Akureyringa til þjónustu Strætisvagna Akureyrar, snjómoksturs, hálfuvarna, svifryks og hreinsunar gatna á Akureyri [Perspective of residents in Akureyri regarding services of public buses, snow clearing, ice prevention, airborne particles and cleaning of streets in Akureyri]	Akureyri.is



Town of Akureyri, n.d.b	Velferðarstefna Akureyrar 2017-2021 Drög til kynningar [Welfare policy for Akureyri 2017-2021, draft]	Akureyri.is
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Each document was read thoroughly, and data were extracted using the software Atlas.ti (version 1.0.30). Questions in Table 10 served as a foundation for data extraction and data analysis. Data analysis occurred in parallel with the data extraction, and on two levels. First, a deductive content analysis (Elo & Kyngäs, 2008) was conducted to identify information about how these service areas are put forth in the documents, and how they appear to be implemented and organized. Second, information from the documents was analysed from an occupational perspective, by looking at how those service areas appear to be affecting peoples' opportunities to engage in various occupation (see Table 10). Findings were first organized around each service area, and then common concerns between the findings were synthesised. For the purpose of trustworthiness, an Icelandic member of the research team who is knowledgeable about the affairs of disabled people in Iceland and the Icelandic system in that field, reviewed the initial findings along with the data source list and gave feedback.

**Table 10: Extracted information**

Bibliographical data		<ul style="list-style-type: none"> <li>• Title</li> <li>• Date of publication</li> <li>• Author/institution</li> <li>• How can the publication be accessed?</li> <li>• Type of material</li> </ul>
Content analysis – based on phase 1		<ul style="list-style-type: none"> <li>• Who is represented in prevailing policy and service development and implementation?</li> <li>• How does the document talk about user’s involvement (look for autonomy, individual centered services etc.)?</li> </ul>
Content analysis based on phase 1	– specific for <b>transportation services</b>	<ul style="list-style-type: none"> <li>• How is provision of the service organized?</li> <li>• What does the document say about provision of the service (for example, time offered, availability, days)?</li> <li>• Who has the right to get these services according to the documents?</li> <li>• When is the service operating?</li> <li>• Who can use it?</li> <li>• Are there limits (for example number of trips, age of service user etc.)?</li> <li>• What can the users use this service for?</li> <li>• Who is responsible for this service?</li> </ul>
Content analysis based on phase 1	– specific for <b>accessibility</b>	<ul style="list-style-type: none"> <li>• What services do affect physical accessibility in Akureyri?</li> <li>• How are they organized?</li> <li>• How is the legislation around accessibility?</li> <li>• How do these documents address awareness or awareness raising?</li> <li>• What do these documents say about universal design/inclusive design/accessibility for all?</li> <li>• How do these documents address issues of accessibility monitoring system (and who does the audits)?</li> </ul>

		<ul style="list-style-type: none"> <li>• New plan of action – will their actions only cover public buildings?</li> <li>• What measures are currently taken to raise awareness?</li> </ul>
Occupational rights and justice (Both service areas)		<ul style="list-style-type: none"> <li>• What occupations do these services areas support?</li> <li>• What occupations do they not support?</li> <li>• Are there any occupational justice and rights values visible in the documents? (Respect for and equitable provision of resources to meet the differing occupational needs of people)</li> <li>• Do people have equal opportunities to do as other people?</li> <li>• Do the services consider different needs of individuals.</li> </ul>

## 4.6 Quality considerations

To reinforce the quality of this case study, I aimed to address all the essential aspects of case study research as identified in chapter three. Those aspects relate to: (1) having a clear description of the case and its context; (2) using multiple sources of data; and (3) making all decisions and actions in the research process explicit for the readers.

A clear definition of the initial case, and the change of that definition in phase two was provided, as well as detailed information about the case's context, or the policy context in Iceland and in Akureyri. Boundaries for the case were also identified to limit the scope of the study (Simons, 2009; Yin, 2014). The case in this study was contextual factors that shape occupation (services, systems and policies), and it was bounded by a certain

occupation (community mobility), specific characteristics of a group (people with mobility impairments), and geographical location (town of Akureyri).

Multiple sources of data were used in this case study. Focus group interviews stemmed from two sources, that is service providers and service users. Policy documents were obtained from multiple websites, both from national and local authorities. By collecting and analysing data from multiple sources, data triangulation can be achieved which helps validate the findings of the case study (Hancock & Algozzine, 2015; Merriam, 1997; Simons, 2009; Stake, 1995; Yin, 2014). Researcher triangulation was also used where other researchers reviewed the data. Additionally, member checking, or seeking feedback from respondents in the research, can be helpful to validate the findings, or the researchers' interpretations and representations (Hancock & Algozzine, 2015; Simons, 2009; Stake, 1995). This was done in this study, by sending an email with summary of the findings to focus group participants who had agreed to be contacted again for the purpose of providing feedback.

Another important aspect of case study research is to give detailed information on the design and process. This can be done by providing thick description and ample details about the whole process, and in that way it can support reliability (Merriam, 1997; Yin, 2014), and credibility (Tracy, 2010). I endeavoured to provide as much details as possible regarding the case, its context, the research questions, data collection, analysis as well as

explaining decisions made, such as regarding how the research questions and the definition of the case changed between phases, and regarding excluding the user controlled personal assistance in the policy review.

Furthermore, rigour was added to the study by prolonged engagement of working with the data, and provision of enough data to support my claims (Tracy, 2010). My prolonged engagement helped me gain insight in the data; conducting the interviews, transcribing them, translating them, and analysing them, helped me to get immersed with the data and become fully familiar with it. I endeavoured to provide enough data to support the claims I make by providing multiple quotes in phase one derived from the transcripts, and by providing citation to every document I used in phase two. Additionally, throughout the research process, peer-reflexivity was used with discussions with my supervisor as well as other advisory committee members. During those discussions, I had the opportunity to discuss my values, beliefs and assumptions.

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## Chapter 5

### 5 Services, systems, and policies affecting community mobility for people with mobility impairments in Northern Iceland: An occupational perspective<sup>3</sup>

In 2007, the Icelandic government signed the United Nations' Convention on the Rights of Persons with Disabilities (CRPD), and ratified it in September 2016 (Ministry of Justice, n.d.). The CRPD directs policy focus towards human rights of disabled people<sup>4</sup> and social perspectives on disability, where the attention is more on contextual factors shaping disability, rather than individuals and their impairments (United Nations, 2006). From an occupational perspective, the principles of the CRPD relate to the concept of occupational justice, which refers to “the promotion of social and economic conditions to increase individual, community, and political awareness, resources and equitable

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<sup>4</sup> The term disabled people is used throughout this text, except in quotations from others. Such terminology is frequently used within disability studies to put emphasis on how people with impairment are disabled by socio-political factors (Shakespeare, 2015; Stone, 2012).

opportunities for diverse occupational opportunities that enable people to meet their potential and experience well-being” (Wilcock, 2006, p. 343). Furthermore, the CRPD principles relate to occupational rights or “the right of all people to engage in meaningful occupations that contribute positively to their own well-being and the well-being of their communities” (Hammell, 2008, p. 62). While occupational justice focuses on the promotion of resources, occupational rights refers to human rights of people to have opportunities to act, or participate in occupation (Hammell & Iwama, 2012).

Participation in meaningful occupation is fundamental for health and well-being (Wilcock & Hocking, 2015). Community mobility can be thought of as both an occupation, and a means to occupation, as it is a prerequisite for taking part in many aspects of society. Community mobility is when people move around in their communities, “in accord with their needs and preferences” (Di Stefano, Stuckey, & Lovell, 2012, p. 98), using various means of transportation (American Occupational Therapy Association, 2014). Thus, community mobility is not only about how people go between places, but why they do it. When community mobility is constrained, it can shape people’s occupation in multiple ways; if people cannot get to the site of a particular occupation, they are prevented from engaging in it. People with mobility impairments have difficulty walking or moving around (World Health Organization, 2001). This article focuses on people with mobility impairments who use some form of mobility devices (wheelchair, walker, cane). These individuals meet specific challenges to

community mobility as the environment does not always accommodate their needs, for example in respect to accessibility and transportation services (Hjelle & Vik, 2011; Layton, 2012; Lid & Solvang, 2016; Meyers, Anderson, Miller, Shipp, & Hoenig, 2002; Mortenson, Hammell, Luts, Soles, & Miller, 2015; Pettersson, Iwarsson, Brandt, Norin, & Månsson Lexell, 2014; World Health Organization, 2011).

Services, systems, and policies can hinder or facilitate occupational engagement in the community. Policies include governmental rules, regulations, conventions, and standards that govern systems that organize, control, and monitor services, such as structured programmes or benefits (World Health Organization, 2001). Little attention has been directed to how services, systems, and policies can better accommodate people with mobility impairment and support their community mobility (Jónasdóttir & Polgar, 2018) although the importance of addressing such macro level factors shaping occupations has frequently been emphasised within the field of occupational science (Galvaan, 2012; Hammell, 2015; Hammell & Iwama, 2012; Pereira, 2014; Rudman, 2012; Rudman & Huot, 2012; Townsend, 2012). In a recent scoping review (Jónasdóttir & Polgar, 2018), only two studies were found that focused especially on those systemic factors affecting community mobility for people with mobility impairments (Ferrari, Berlingerio, Calabrese, & Reades, 2014; Jónasdóttir & Polgar, 2018.; Kántor-Forgách, 2010). Both studies focused on public transportation for people with reduced mobility, although not



from the users' perspectives. The most frequent barriers identified in the scoping review were related to transportation, open space planning, and architecture and construction (Jónasdóttir & Polgar, 2018).

Two small-scale studies exploring contextual factors affecting participation for people with mobility impairments, were conducted in the capital area of Iceland, and several issues regarding accessibility to the built environment, transportation services, governmental policies, and public attitudes were identified. In both studies lack of community mobility affected participants' work, school, and leisure occupations (Árnadóttir, 2013; Kristjánsdóttir, Benediktsdóttir, & Jónasdóttir, 2008). No similar studies have been done in northern Iceland, where the population is smaller, resources are different, and weather conditions can be harsher. Therefore, the main objective of this study was to identify services, systems, and policy barriers, and potential solutions, to improve community mobility for this group in the town of Akureyri, in Northern Iceland. A secondary objective was to understand the relationship among these infrastructure factors, community mobility, and occupation.

## 5.1 Methods

This paper describes the first phase of a pragmatic exploratory case study, where the single-case under examination covers the implementation of any Icelandic services,

systems, and policies that restrict or support community mobility for people with mobility impairments in Akureyri. Case study methodology was selected as it aligns with looking at a specific bounded case from various perspectives (Merriam, 1997; Simons, 2009; Stake, 1995; Yin, 2014), where the case can be a complex contemporary social and political phenomenon in the society (Yin, 2014).

### 5.1.1 The bounded case

Akureyri, is located on a mountainside, just south of the arctic circle, with short bright summers and harsh, long, dark winters. It is the largest town in Northern Iceland with a population of about 18,000 people (Statistics Iceland, 2016). Around 15.4% of disabled people in Iceland, who are 18 years or older and receive services from local authorities, have mobility impairment. Thus, the estimated number of people with mobility impairments in Akureyri is around 70 individuals (Statistics Iceland, 2014).

The responsibility for organizing, implementing, and monitoring services for disabled people in Iceland was transferred from national to local authorities in 2011, although national authorities remain in charge of policy formulation in the field (Act no. 152/2010; Act no. 59/1992). However, local authorities in Akureyri have been responsible for disability services since 1996 (PricewaterhouseCoopers, 2000). Their work has been considered exemplary for integrated welfare services in Iceland. In recent years, an important debate has taken place in Iceland concerning implementation of independent

living ideology in the welfare system, which is based on people's rights to have control over own lives, choices and equal opportunities (Ratzka, 2012).

### 5.1.2 Data collection

Three focus groups were conducted in the town of Akureyri. Focus groups can be helpful when evaluating and developing policies and services, and when ideas are needed to emerge from a group (Krueger & Casey, 2009). A case should be looked at from different perspectives, preferably using multiple methods (Merriam, 1997; Simons, 2009; Stake, 1995; Yin, 2014) which includes focus groups and other methods of data collection from participants. Thus, the findings from these focus groups will help to bound the case to specific services, systems and policies identified by stakeholders to guide data collection in the next phase of the case study.

### 5.1.3 Participants and recruitment

Fourteen individuals participated in the focus groups. Eight service users aged 18 years or older, with at least 18 months experience of using mobility devices on a daily basis and regularly attending community venues, were divided into two groups (four in each group). Six service providers, with at least two years experience of providing and/or planning services for disabled people in the area, and interacting with people with mobility impairments in their work, took part in the third group. To ensure anonymity,

participants are not described in details; however their main characteristics, along with background information can be seen in Table 11.

**Table 11: Characteristics of participants and background information**

	Service users
Gender	3 women 5 men
Age	18-24 years = 1 35-44 years = 1 45-54 years = 2 55-64 years = 1 65-74 years = 3
Use of mobility device	Wheelchair = 5 (powered = 2) Walker = 1 Both = 2
Experience of using mobility device	2-5 years = 2 5-10 years = 2 More than 10 years = 4
Employment status	Working = 4 Not working = 4
Living situation	2 live alone 1 lives with parents, 5 live with spouse/partner
How participants go between places within the community	Drive themselves = 5 Public transportation (such as bus) = 1 Transportation service (available for people who cannot use public transportation) = 4 Driven by someone = 4 Wheelchair or walker = 3

<b>Service providers</b>	
Gender	5 women 1 man
Age	25-34 years = 1 45-54 years = 3 55-64 years = 2
Work experience	All have more than 10 years' experience of working with disabled people. All have experience in management or consultation in the field, and insight into available services and systems

After obtaining ethics approval from both the National ethics board of Iceland (certificate nr. 14-089 CM) and the Western University research ethics board (certificate nr. 105537), participants were recruited using purposive sampling. A gatekeeper within the Association of Disabled People helped identify potential participants for the service users' groups by providing them with the study information letter and, with their permission, sending the first author their contact information. Potential participants for the service provider group were sent an e-mail after being identified by a person with lengthy experience of working within the disability service sector in Akureyri. The first author answered any questions participants had over the phone and obtained informed written consent at the time of focus group discussion, prior to collecting data.

#### 5.1.4 Data collection and analysis

The first author moderated all focus group interviews, which took place in December 2014 and lasted between 1-2 hours each. Questions focused on services, systems, and policy factors affecting community mobility for people with mobility impairments; for example, how they move between places, where they want to go, where they cannot go, the barriers and potential facilitators, and key considerations for developing services, systems, and policies to support community mobility.

Interviews were conducted in Icelandic, digitally audio recorded, and transcribed verbatim by the first author. Transcripts were translated into English as one member of the research team (the third author) does not read/understand Icelandic. The emphasis of the translation was on conveying the sense of the text, rather than word-for-word, as verbatim translation has the potential to obscure the meaning in English. The second author, who is fluent in both Icelandic and English, performed an audit (see below) to determine whether the Icelandic and English versions of the transcripts conveyed similar data.

Inductive content analysis (Elo & Kyngäs, 2008; Hsieh, 2005) informed by the formal data-structure analysis approach (FDSA) (Borell, Nygård, Asaba, Gustavsson, & Hemmingsson, 2012; Gustavsson, 1996) was used. FDSA is a multi-level interpretive approach, based on hermeneutic tradition, that allowed the researchers to reflect on their

own experiences when interpreting the data. Throughout the analytic process interpretations were guided by an occupational perspective, as we were “looking at or thinking about human doing” (Njelesani, Tang, Jonsson, & Polatajko, 2014, p. 233). More specifically we were looking for the relationship between community mobility and occupation, understanding how available resources influence community mobility and thus indirectly opportunities to engage in other meaningful occupations. We then considered these findings from an occupational perspective, bringing in key ideas of occupational justice and rights (Hammell, 2008; Wilcock, 2006) and linked them to principles of the CRPD (United Nations, 2006).

The data were reviewed multiple times and manually coded and recoded, using the data analysis software *Atlast.ti* (version 1.0.30). Initially, the original Icelandic version of the data were coded by the first author and the English version by the third author. Team members then met to discuss their independent coding. All reasonable interpretations of the data were then formulated, organized into themes and tested against the original transcripts with the purpose of verifying if the interpretations were supported by the data (Gustavsson, 1996). The salient features of included quotes were discussed to develop the labels of the themes.

One measure of trustworthiness used was review of the Icelandic transcripts, the joint codes and themes developed by the first and third author, and notes supporting the

analysis by the second author who is fluent in both Icelandic and English. Her review confirmed that the themes and interpretation were reflective of the original data in the transcripts and that no new themes were emergent. A second measure of trustworthiness involved seeking reflections on the analysis from several participants who agreed to be contacted for this purpose. Responses came from three service providers, confirming the initial analysis. The lack of response from service users may relate to the time elapsed, as almost a year had passed before feedback was sought. The third measure of trustworthiness was peer-reflexivity, which was done through continuous discussions within the research team regarding the perspectives we bring to the research as well as our data collection and analytic process.

### 5.1.5 Positioning of researchers

The first author's position within this research is complex as she brings in the perspective of a researcher alongside past experiences of living and working in Akureyri for several years. She is a former employee of the system working with disabled people and an advocate for the rights of the same group. However, neither she nor the other authors did have any relationship with the participants prior to the research. The second author brings a disability studies perspective. All authors are occupational scientists with an occupational therapy background.



## 5.2 Findings

The five themes identify barriers and highlight important aspects that authorities need to consider and implement in policy to better support community mobility. The themes are: “Being mobile: a key to meaningful occupations”, “Users as agents in their own lives”, “Means of transportation”, “Accessibility awareness”, and “Integration of services and systems”. Presented quotes may reflect an Icelandic manner of phrasing, particularly when changing the words would alter the speaker’s intent.

### 5.2.1 Being mobile: a key to meaningful occupations

All participants stressed the importance of having opportunities to move between places in the community, as it is foundational for engagement in many meaningful occupations and full participation in society. They considered community mobility important to access different occupations, and for its own value, such as when people wanted to take a ride to enjoy the sunny weather. It was apparent that community mobility is a dynamic situation where people, depending on the day, may have different preferences and needs for going between places, such as fewer needs when their energy level is low, or more when invited to participate in multiple events. All groups discussed how engagement in different societal occupations depended on their opportunities to get into the community. Organized occupations, or those scheduled beforehand, like going to work and seeking

health services or training, were easiest for the group to access, due to fixed schedule of services.

However, there was also evidence of occupation being impacted by the negative effects of mobility issues. In many cases, due to lack of community mobility, people were unable to engage in meaningful occupation, for example work, run errands, seek health services, travel, and social, cultural, and outdoor occupations. Furthermore, due to rigid and inflexible services, users could not go anywhere spontaneously or act at the time of their choice in ways that other people might take for granted, such as going home from work earlier if unwell. Occupations that mainly took place in the evening and on weekends such as going to the theatre, movies, concerts, and night-clubbing were particularly affected because of lack of services during those times. A user explained “*it affects of course that you maybe do not go somewhere... or do not do something that you would [otherwise] do on weekends*”. Other service users similarly commented on how flaws in the service system hindered their community mobility and restricted their options to participate in cultural events in society.

Service users expressed frustration or disappointment when they could not participate in what their friends were doing or was considered typical to do in society, such as going to the movies. A wheelchair user said, “*you get frustrated or upset if something in the environment stops you, or the disability... makes you unable to be part of the group*”.

When asked how the system could support community mobility, an experienced service provider highlighted the importance of flexibility in service provision so *“people can experience what they want to experience”*. Others agreed and one participant asserted the need to *“have the opportunities to experience like other people that do not have mobility limitations”*, emphasising that everyone should have equal opportunities in society.

### 5.2.2 Users as agents in their own lives

The users wanted more control over their lives and the services they received. They stressed that policy and service design should focus on their diverse needs and values to support them to move around in the community. A strong consensus in all groups affirmed that disabled people should be recognised and actively involved in development of all services that concern them: *“that service aims at serving the needs of disabled people. I consider this very important. Sometimes it is said ‘nothing about disabled people without us’. This is just one example that disabled people should join the discussion”*. (Service user)

Autonomy and individually centred services were highlighted in all the groups, as a service user said *“the question about services for disabled people is the question about if we can have individually centred services which aim... where the control comes more from the disabled person”*. Service users were upset about services that were not tailored to them, and one put it simply, *“not only are you disabled, but also have to use services*

*that do not suit you”* (Service user). The main service areas participants wanted to be able to direct more were related to transportation, personal assistance services, and infrastructure services that affect accessibility.

Personal assistance was repeatedly discussed as a service form that is individually centered and gives people autonomy regarding when and where to go. Often people simply need someone to go with them on the bus or to drive them somewhere. One form of personal assistance that was stressed is NPA (notendastýrð persónuleg aðstoð or user-controlled personal assistance), which is a pilot project inspired by ideas from the Independent Living Movement, where users get funding from local authorities to hire their own personal assistants. The service users mainly highlighted positive aspects of NPA; one user who had experience of such setup explained “*yes you have more control of your life... and I find that ... absolutely great. I just have assistance, can use it for something that you could never get in the normal system*”. The service providers, on the other hand, were more sceptical and found NPA complicated in practice, which might be explained by their experiences of systemic restraints to NPA. However, they stressed the importance of user-controlled services:

*user-controlled service is clearly the thing. Service on your terms when it suits you... with people that you trust, people that you choose. I just think that*

*consequentially helps you access the whole life. To all institutions, to everything... basically whatever you want to do. (Service provider)*

Service providers also agreed on the importance of including autonomy and independent living ideology in the public service system so that users can control who assists them, when, where and how.

Consulting with people with mobility impairments, when altering the built environment, was also discussed. A wheelchair user said “...*when houses are built or modified or designed, they bring in some architects and some people with those great degrees. Why don't they consult a disabled person who uses wheelchair*”? The service providers wanted people with various impairments to be involved in the process as they have different needs that must be considered. This point of view can possibly be explained by service providers working with diverse groups of people, not only people with mobility impairments. Nonetheless, both perspectives speak to the point of consulting users, and applying their input in the design and development of the built environment.

### 5.2.3 Means of transportation

Discussions reflected the need for providing accessible, flexible, and affordable means of transportation. Most public vehicles, such as buses and taxis were not accessible. The service users suggested changes in the regulatory environment to better accommodate

people: “*they should at least have a car [for public service] that can take disabled people and wheelchairs inside it*” (Service user). The service providers had similar discussions:

*of course, it should just be a taxi that operates for all, and if not ordered for a wheelchair then it goes to the next party. It’s just a taxi, like on Tenerife [Tourist destination in Canary Island], where they are not labeled “wheelchair taxi” but “taxi for all”, that’s cool.* (Service provider)

Participants who had applied for assistance from the Social insurance system to buy accessible cars, or get alterations on their cars, struggled with overwhelming bureaucracy and restricted regulations. A car buyer explained “*I wanted to get an adaptor... for easy fastening of the chair. But because I do not drive myself then I cannot get it*”.

Additionally, the subsidy amount they could apply for when buying a new car had not increased in proportion with the prices of cars in recent years.

All the groups were highly focused on how lack of flexibility in the transportation service restricted community mobility for the users. Most users had the same schedule with the transportation service every week to go to certain places like work, school, or health service locations. However, users considered it unacceptable how the transportation service did not operate on weekends and stopped operating early in the evenings. They were very dissatisfied with having to order the transportation service at least 24 hours in

advance and suggested that having an accessible car, which could be ordered with short notice, would improve the transportation service and give people the chance to go between places on weekends, evenings, and without planning every movement in advance.

Participants also stressed that affordable means of transportation at all hours would greatly improve people's community mobility. Taxi services were considered too expensive, especially as that was the only option many people had in the hours when the transportation service was not operating. High cost of traveling was also emphasized, caused by having to pay double or triple airfares as people have to pay for personal assistants as well as for themselves. One user said ironically: "*I have the privilege to have to pay double when I go abroad. I need an assistant*". Local authorities covered part of assistants' salary in such trips, but the users had to front the difference as well as the living expenses for the assistants. Some suggested that the welfare system should set up a fund where people could apply for support and airfares would be distributed as per quota.

#### 5.2.4 Accessibility awareness

All groups considered accessible surroundings essential to support peoples' community mobility. Hindrances caused by design or structural flaws in the built environment, or obstacles on pavements were repeatedly described. Service users did not feel welcome or as valued citizens in such situations, as one service user explained, "*well we are actually*

*in the same position as a non-disabled person who has to run errands on 3rd floor in a house and there are no stairs or elevator, only rope from the window*". Weather related factors and unsatisfactory snow removal also limited community mobility, for instance when snow was shovelled into the parking spot for disabled persons, or sidewalks were only partially cleared. In addition to causing difficulties with community mobility, some barriers placed people in an unsafe situation, such as when forced into traffic by obstacles on sidewalks.

Most of the barriers were considered to be caused by thoughtlessness or lack of awareness, such as when the appearance of a building was more important than the different needs of people who used it. One example a wheelchair user described was when his friend, who was assisting him to modify his house, found it more important for the aesthetics to have stairs than a ramp. Other examples included access to buildings being blocked because Christmas trees or "offer of the day" signs were positioned on top of the ramps. Participants recounted experiences that suggested to them that others held the attitude "no worries, we will help you" or that accessibility is not important. A wheelchair user gave an example of wanting to access a social event, but the parking space was covered with snow. When asking why the snow had not been removed, the answer was *"it is just too expensive... just call us when you come and we will carry you inside"*. Participants obviously disliked such an approach, as they wanted to be independent.



Service users experienced that other people do not understand how it is to be disabled. When asked what needed to change to move things forward, a user replied, “*change of public attitude in the society would be a big step... that people would consider disabled people as normal... [and] include us in society*”. Better dissemination of information regarding accessibility hindrances and possible improvements was suggested as a tool for raising awareness, both for general public and people who work within the service system. Furthermore, service providers emphasised that people should speak out and not act like everything is okay, if it is not. For instance, they should insist that obstacles are removed to bring people’s attention to the problem it causes.

The idea of “accessibility for all” came up in all discussions as the ideal situation, and one user commented “*it’s this peculiar idea about accessibility for this one and accessibility for the other... It’s supposed to be accessibility for all. We are all human and should all be included. So this is just outdated thinking*”. The service providers agreed that it is pointless to talk about accessibility for certain groups – people should simply refer to it as accessibility, as it is all peoples’ right to have accessible surroundings.

### 5.2.5 Integration of services and systems

People expressed a range of views that reflected the need for enhanced integration of services at the system level. Integration between the transportation service and the taxis

was especially important. The positive aspect of collaboration between those services, which took place when the transportation service asked for assistance to cover organized trips, was acknowledged, but not considered sufficient. Participants suggested that local authorities, which are responsible for services for disabled people, fund or offer a significant taxi subsidy to cover transportation service at all times. As a user said, “*that would remove the Achilles’ heel of the transportation service so it would work smoothly*”.

Participants also stressed the importance of integration between services and physical accessibility. Places may be physically accessible, but if someone who needs personal assistance is not provided with such service, in reality the place might not be accessible. Likewise, integration between transportation and snow removal services was important:

*one action is taken and then probably not another one and for sure not the third one in many cases. It is great to have a bus stop and [an accessible bus]... But then it must be well cleared of snow like in this town, you have to be able to get to the bus stop. (Service provider).*

The service providers suggested more communication between and within various service departments of the municipality to increase integration between service areas. One example illustrated how better communication could prevent situations such as when the transportation service cannot pick up users due to lack of snow removal, especially since

those services are based within the same department. They also gave examples of how poor exchange of information between service departments caused accessibility issues, and thus mobility hindrances, such as when experienced and knowledgeable people working in the field were not consulted regarding the design of buildings. Even when consultation was sought, the message got lost on the way, leading to mistakes that limit accessibility. The service providers wanted all people who work within the disability service sector to be aware of, and better communicate the needs of, disabled people among each other. Even though the departments have different roles within the service system, they collaboratively shape the environment of disabled people in the area, with direct services like the transportation service and personal assistance, or indirect services such as snow removal and alteration of the built environment.

### 5.3 Discussion

From service users' and providers' perspectives, community mobility for people with mobility impairments in Akureyri can be supported by incorporating five important aspects into policy implementation. First, community mobility is key to having opportunities to engage in meaningful occupations and participate in society. Second, users should have control over and be involved in making decisions and developing services that affect them. Third, people need flexible, accessible, and affordable means of transportation to have the opportunities to go where they need to go, when they want.

Fourth, measures need to be taken to raise awareness of what accessibility means, why it is important and how it can be managed. Lastly, the system has to be looked at holistically for better integration to strengthen the different service areas for disabled people.

In addition to identifying possible ways to better support community mobility, the findings also highlight the importance of community mobility for supporting participation in other occupations. As emphasised in the CRPD, disabled people should be included in society and have opportunities to participate on an equal basis with others in all aspects of life, including work, political, public and cultural life, recreation, leisure and sport (United Nations, 2006). Still, people with mobility impairments in Akureyri are not fully included in society as they are underprivileged by structural factors that limit their opportunities to access and enjoy participation in meaningful and desired occupations in some aspects of their life, such as cultural life and recreation. These findings reveal injustices (Wilcock, 2006), and violation of occupational rights (Hammell, 2008) and highlight the importance of incorporating occupational justice and rights values into policy implementation in Iceland to support community mobility.

A change towards occupational justice and rights can only be achieved by providing the resources and opportunities needed for people to access occupations that are meaningful to them. An example of change is to integrate in legal text, and ensure it is translated into

practice, a range of meaningful occupations (not limited to work, school, and health care activities) that specific resources (such as the transportation service or personal assistance) should support. By defining the occupations that resources should legally support, the results will be twofold, as those resources will also support community mobility. The factors that preclude people from moving around and participating in occupation need to be addressed by Icelandic authorities, when they review and amend legal texts, services, systems and policies to meet the requirements of the CRPD (United Nations, 2006), as intended to do by the year 2021 according to the new policy on disabled peoples affairs in Iceland (Resolution no. 16/146, 2017).

As presented in article 20 of the CRPD, disabled people should have access to affordable transportation and the opportunities to move around at the time of their choice (United Nations, 2006). People should not have to prioritise their work and health service appointments over being able to participate in cultural, social and leisure occupations on evenings and weekends, or any spontaneous occupations, identified as personally meaningful. Why the system favours productive occupations is unclear and needs to be explored further. Yet, this limiting setup implies that there are some underlying assumptions about what occupations are considered important in life, shaping the transportation service and causing disabled people to be occupationally marginalized as they cannot engage in occupations that the system does not support. Even though work is

considered important for many people, other occupations, such as leisure, should be equally valued in society (Hammell, 2009).

Echoing the CRPD, participants articulated that disabled people should have control over services that are specifically directed to them, and be involved on a broader level where they can effect policy implementation (United Nations, 2006). The findings are in line with previous literature emphasizing that users are not as involved in service development and decision making as they want to be (French & Swain, 2012; Rice, Björnsdóttir, & Smith, 2015). Similarly, a recent study shows that 46% of disabled people in Iceland find they have little control over the services they receive (The Social Science Research Institute, 2014). These findings are striking as the smallness of the society and the close proximity of service users and officials could easily support such involvement, and with the upcoming changes in law, policies and practices – following the implementation of the CRPD – this should be improved. Parallel to our findings, disability studies scholars have reported on service users being satisfied with user-controlled personal assistance, as it gives them autonomy, but problems continue to exist from authorities' perspective regarding funding and distribution (Barnes & Mercer, 2006; Brennan, Rice, Traustadottir, & Anderberg, 2016; Ellis, 2007; French & Swain, 2012). This raises questions about power relations between service users, service providers, and officials, such as whose voices are heard and who is represented in prevailing policy and service development and implementation.

The participants called for *accessibility for all*, which relates to the terms *design for all*, and *inclusive* and *universal design* which have been used interchangeably for design that aims to serve the whole population (Conway, 2008; Ostroff, 2011). Embracing the diversity of people, the CRPD highlights the importance of universal design as “the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible” (United Nations, 2006, p. 4). Such design has to be based on the complex interplay between people and their environment where users’ perspectives and their embodied experiences are embraced in the design process (Lid, 2013; Story, 2011). Still, disabled people are not typically involved in such processes, often due to attitudes of property developers and professionals (Hjelle & Vik, 2011; Imrie & Hall, 2001).

The need for universal design within Nordic countries has also been emphasised by the Nordic Centre for Welfare and Social Issues (2010) to enable disabled persons to take part in culture and education, and to have access to goods and services. Universal design is not only about the practical aspect of fixing accessibility, but is a political strategy which intends to raise awareness in society (Story, 2011), an aspect raised by all study participants. The CRPD puts emphasis on awareness raising and that state parties should take appropriate measures so disabled people have the same access to the physical environment and transportation as other people (United Nations, 2006). Informing service providers and the whole society about their legal obligations regarding accessibility (Act

no. 160/2010) can raise awareness, and push people to make simple, but critical, changes that are needed, such as putting up a simple ramp, removing an obstacle or clearing sidewalks and parking spaces of snow.

The CRPD further requires its state parties to have an active system that monitors accessibility (United Nations, 2006) and, if audits are done by disabled people (as recommended by the World Health Organization, 2011), such a system has the potential to improve accessibility and raise awareness in society. Such a monitoring system is currently in its infancy in Iceland. Authorities are encouraging the public sector to appoint a representative, who would be responsible for monitoring accessibility and make plans for improvements (Resolution no. 16/146, 2017). Questions remain unanswered whether such an arrangement will only cover public buildings, or if it will be extended to other facilities. Furthermore, it is unclear if any additional measures are currently taken to raise awareness of accessibility issues in society.

Our findings highlight the importance of interactions of different systemic factors to support community mobility. These influential factors cannot be implemented and developed in isolation, the integration needs to be embraced within the whole service system, across service areas, such as transportation, snow removal, personal assistance, and alteration of built environment. The findings also indicate that communication is essential to increase such integration, which raises questions about the effectiveness of



interactions among different service areas in the present system, and strategies to increase integration of those services. No chain is stronger than its weakest link. According to Article 4 of the CRPD, services should be improved by promoting training of service providers who work with disabled people (United Nations, 2006). Such training could be a valuable start for better integration of services, and communication of community mobility issues and solutions for the group. In addition to such training, the system might be improved by having clear procedures and policies regarding communication between and within service departments.

Interestingly, service providers were in agreement with service users on most of the aspects discussed. Still, many barriers exist within the system that limit opportunities for community mobility of people with mobility impairments, which raises questions about why these barriers persist and what causes them. It is necessary to focus future research on specific policy implementation areas, namely transportation services, personal assistance, and infrastructure services affecting accessibility. For example, research should focus on to what extent these barriers originate from policy and legal issues at national level, practices at local level, fiscal restraints, or something else. Further study is required of the legislation, the current system as the implementation of the law, and its congruence with the CRPD. For example, are occupational justice and rights values demonstrated in the written texts, even though not apparent in the implemented services? Furthermore, it is important to explore how these policies and practices are developed,

how decisions are made, and what informs the decision making. For example, how are service users involved in the process? Additionally, hearing the perspectives of officials, from the local and national authorities responsible for developing the above mentioned policies and services, and allocating financial resources, would be of value, as most of the service providers in this study did not have such responsibilities.

Although there is a system in place that intends to support community mobility, people still experience barriers to occupational engagement due to flaws in that system. Our findings point out some causes of these barriers and help to frame the next phase of this case study, which will include a review of policies and other public documents. The aim of that review is to explain why community mobility support services are offered and organized as described in this study. Collectively, these two sources of data will help identify future research and activities aimed at improving community mobility for service users.

### 5.3.1 Limitations

Findings of this study are based on information from a small sample of people in specific geographical context and cannot be generalized. Furthermore, the results were informed by only two parties, service users and service providers, and thus neither reflect perspectives of other key stakeholders, nor policy analysis. However, the findings give valuable information about possibilities to improve community mobility for people with

mobility impairments in the town of Akureyri, Iceland, and may give ideas on how community mobility can be supported on a national level and in similar contexts in other countries.

### 5.3.2 Conclusion

This study contributes to the occupational science literature by providing insight into how community mobility, both as an occupation and as a means to other meaningful occupations, is shaped by macro level factors, and suggests how services, systems, and policies can better support community mobility. Furthermore, the findings show how the limited resources for community mobility restrict the opportunities of people with mobility impairments to engage in meaningful occupation, effectively leading to occupational injustice and violation of their occupational rights.

All themes presented in our findings are touched on in the CRPD. The convention can serve as powerful tool for scholars within the occupational science field to identify violation of occupational rights, and promote changes that incorporate occupational justice and right values into policy design. By sharing knowledge, raising awareness in society, and having discussions with policy developers, occupational scientists and people within the policy making field can work together towards equality and human rights of all people.

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## Chapter 6

### 6 Review of accessibility and transportation policies in Iceland

The intention of this second phase of the study is to understand the services, systems and policies that pertain to certain service areas, that is physical accessibility to the built environment, public transportation and accessible transit services for disabled people. As a reminder, “*Policies govern and regulate the systems that organize, control and monitor services...in various sectors of society*” (World Health Organization, 2001, p.192). Thus, the intention is to gain such understanding through exploring Icelandic policies (including legislations, regulations etc.), and the services as implementations of the policies. In other words, the objective is to explore how would these services look like if they are implemented as described in legal texts and other public policy documents from national and local authorities.

The research questions for this phase were the following:

- How do legal texts, policies, and other public documents from national and local authorities depict transportation services for disabled people in the town of Akureyri, Iceland

- How do legal texts, policies, and other public documents from national and local authorities depict services affecting physical accessibility in the town of Akureyri, Iceland?

Details of the data collection and analysis methods are presented in chapter four. However, table 12 provides an overview of the key documents used for each section of the findings. Chapter four provided detailed information about the policy context in Iceland, and some of the key documents used in this phase were introduced there. As a reminder (as those documents are often referred to), there are two plans of action, the former which was valid from 2012 – 2016 (Resolution no. 43/140, 2012), and a newer plan of action valid from 2017 – 2021 (Resolution no. 16/146, 2017). Additionally, when the newest changes in legislation are mentioned, it refers to amendment to the act on social services provided by local authorities (Act no. 37/2018) which was approved in April 2018 and took effect on October 1<sup>st</sup>, 2018. This amendment was approved at the same time as a new act regarding services for disabled people with long-term needs for support, which replaces an older act on services for disabled people and incorporates changes that align closer to the principles of the CRPD (Act no. 38/2018; United Nations, 2006).



**Table 12: Overview of key documents used for each section of the findings**

<i>Accessibility</i>	
Resolution no. 16/146, 2017	Þingsályktun um stefnu og framkvæmdaáætlun í málefnum fatlaðs fólks fyrir árin 2017-2021 [Resolution on a policy and plan of action on disabled people's affairs for the years 2017-2021]
Act no. 160/2010	Lög um Mannvirki [Building code act]
Regulation no. 112/2012	Byggingarreglugerð [Building code regulation]
Iceland construction authority, n.d.	Leiðbeiningar við byggingarreglugerð [Guidelines for the building code regulation]
Iceland construction authority, 2014	Verklagsregla [Procedure policy]
Iceland construction authority, 2018a	skoðunarlisti öryggisúttektar [Inspection list for safety inspection]
Iceland construction authority, 2018b	skoðunarlisti lokaúttektar [Inspection list for final inspection]
Iceland construction authority, 2018c	skoðunarlisti – hönnunar [Inspection list for design inspection]
Town of Akureyri, 2018b	Aðalskipulag Akureyrar 2018-2030 [Main land use plan for Akureyri 2018-2030]
Town of Akureyri, 2018c	Snjómokstur og hálkuvarnir [Snow clearing and prevention of icy road conditions]
University of Akureyri research centre, 2017	Viðhorf Akureyringa til þjónustu Strætisvagna Akureyrar, snjómoksturs, hálkuvarna, svifryks og hreinsunar gatna á Akureyri [Perspective of residents in Akureyri regarding

	services of public buses, snow clearing, ice prevention, airborne particles and cleaning of streets in Akureyri]
Town of Akureyri, 2012b	Samþykkt fyrir samstarfsnefnd um ferlimál fatlaðra [Agreement regarding joint committee on mobility issues for disabled people]
Town of Akureyri, n.d.a	Ferlinefndar fundargerðir [Accessibility committee – Minutes from meetings]
Resolution no. 43/140, 2012	Þingsályktun um framkvæmdaáætlun í málefnum fatlaðs fólks til ársins 2014 [Resolution on a plan of action on disabled people's affairs to the year 2014]
Town of Akureyri, n.d.b	Velferðarstefna Akureyrar 2017-2021 Drög til kynningar [Welfare policy for Akureyri 2017-2021, draft]
<b><i>Public transportation</i></b>	
Act no. 28/2017	Lög um farþegaflutninga og farmflutninga á landi [Act on onshore passenger transportation and freight transport]
Act no. 59/1992	Lög um málefni fatlaðs fólks [Act on disabled people's affairs]
Act no. 37/2018	Lög um breytingu á lögum um félagsþjónustu sveitarfélaga, nr. 40/1991, með síðari breytingum (innleiðing samnings Sameinuðu þjóðanna um réttindi fatlaðs fólks, stjórnsýsla og húsnæðismál [Act on amendment on the act on social services provided by local authorities (integration of CRPD, administration and housing affairs)].
Resolution no. 16/146, 2017	Þingsályktun um stefnu og framkvæmdaáætlun í málefnum fatlaðs fólks fyrir árin 2017-2021 [Resolution

	on a policy and plan of action on disabled people's affairs for the years 2017-2021]
Resolution no. 43/140, 2012	Þingsályktun um framkvæmdaáætlun í málefnum fatlaðs fólks til ársins 2014 [Resolution on a plan of action on disabled people's affairs to the year 2014]
Ministry of Welfare, 2016	Framkvæmdaáætlun í málefnum fatlaðs fólks 2012-2014. Stöðu- og árangursmat [Plan of action on disabled people's affairs 2012-2014. Status and impact assessment]
Regulation no. 475/2017	Reglugerð um gildistöku reglugerðar Evrópuþingsins og ráðsins (ESB) nr. 181/2011 frá 16. febrúar 2011 um réttindi farþega í hópþingum og um breytingu á reglugerð (EB) nr. 2006/2004. [Regulation on ratification of the European parliament and union regulation nr 181/2011, from February 16th, 2011 regarding the rights of passengers in buses and amendment on regulation nr. 2006/2004]
Regulation no. 181/2011	Reglugerð Evrópuþingsins og ráðsins (ESB) nr. 181/2011 [European parliament and union regulation no 181/2011]
Sjálfstjórn, 2017	Viðbótarumsögn um frumvarp til laga um Farþegaflutninga og farnflutninga lagt fyrir Alþingi á 146. löggjafarþingi 2016-2017. Þskj. 187 - 128. Mál. [Sjálfstjórn – Association of people with mobility impairments – additional comments on resolution regarding onshore passenger transportation and freight transport, on 146. Congress in the Parliament 2016-2017. Parliamentary document no. 187 - Case 128]
Act no. 120/2012	Lög um Vegagerðina, framkvæmdastofnun samgöngumála [Act about the Icelandic road and coastal administration]

Town of Akureyri, 2018	Strætó [Buses]
Akureyrarstofa, 2018	Leiðabók SVA frá 1. febrúar 2018 – tímatöflur [Routes guide SVA from February 1st, 2018 – timetable]
University of Akureyri research centre, 2017	Viðhorf Akureyringa til þjónustu Strætisvagna Akureyrar, snjómoksturs, hálkuvarna, svifryks og hreinsunar gatna á Akureyri [Perspective of residents in Akureyri regarding services of public buses, snow clearing, ice prevention, airborne particles and cleaning of streets in Akureyri]
Town of Akureyri, 2016a	Samstarfsnefnd um ferlimál fatlaðra, 1. Fundur, 7. Mars 2016 [Joint committee on transportation for disabled, 1st meeting, March 7th, 2016]
Town of Akureyri, n.d.c	Úttekt aðgengismála að strætisvögnum og SVA [Assessment of accessibility to buses and bus stops]
Town of Akureyri, 2017b	Umhverfis- og samgöngustefna [Environmental- and transport policy]
Town of Akureyri, 2012a	Samstarfsnefnd um ferlimál fatlaðra, 1. Fundur, 10. september 2012 [Joint committee on transportation for disabled, 1st meeting, September 10th, 2012]
<i>Accessible transit services for disabled people</i>	
Act no. 59/1992	Lög um málefni fatlaðs fólks [Act on disabled people's affairs]
Act no. 37/2018	Lög um breytingu á lögum um félagsþjónustu sveitarfélaga, nr. 40/1991, með síðari breytingum (innleiðing samnings Sameinuðu þjóðanna um réttindi fatlaðs fólks, stjórnsýsla og húsnæðismál [Act

	on amendment on the act on social services provided by local authorities (integration of CRPD, administration and housing affairs)].
Ministry of Welfare, 2012	Leiðbeinandi reglur fyrir sveitarfélög um ferðaþjónustu fyrir fatlað fólk, samkvæmt lögum nr. 59/1992, um málefni fatlaðs fólks, með síðari breytingum [Guidelines for local authorities regarding transportation service for disabled people, based on Act. no. 59/1992, on disabled people's affairs, with last amendments]
Town of Akureyri, 2010	Reglur um akstursþjónustu á Akureyri [Policy on transportation service in Akureyri]
Town of Akureyri, 2013b	Ferliþjónusta Akureyrar - Könnun um ánægju notenda, 6-67 ára [Transportation service of Akureyri – Survey on users' satisfaction, 6-67 years old]
Town of Akureyri, 2017a	Ársskýrsla Akureyrarbæjar 2016 [Annual report for the town of Akureyri 2016]
Town of Akureyri, 2013a	Ársskýrsla Akureyrarbæjar 2012 [Annual report for the town of Akureyri 2012]
Town of Akureyri, 2015	Ársskýrsla Akureyrarbæjar 2014 [Annual report for the town of Akureyri 2014]
Town of Akureyri, 2014	Ársskýrsla Akureyrarbæjar 2013 [Annual report for the town of Akureyri 2013]
Town of Akureyri, 2018	Strætó [Buses]
Parliament, 2018	Öll erindi í 27. máli: félagsþjónusta sveitarfélaga [All comments on amendments on the act on social services provided by local authorities]
Welfare committee, 2018	Nefndarálit um frumvarp til laga um þjónustu við fatlað fólk með miklar stuðningsþarfir og frumvarp til laga um

	breytingu á lögum um félagsþjónustu sveitarfélaga [Committee report on resolution regarding act on services for disabled people with extensive need for support, and resolution regarding amendments on the act on social services provided by local authorities]
Akureyrarstofa, 2018	Leiðabók SVA frá 1. febrúar 2018 – tímatöflur [Routes guide SVA from February 1st, 2018 – timetable]
SVA, 2016	Leið 6: Síðuhverfi-Naustahverfi [Route 6: Síðuhverfi-Naustahverfi [Route 6 - Map of a bus route in Akureyri]
Town of Akureyri – department of residence, 2017, p.1	Umsókn um akstursþjónustu [Application for transit service]
Althing ombudsman, file no.9160/2016	Álit og bréf - Mál nr. 9160/2016 [Comment on case no 9160/2016]
Resolution no. 43/140, 2012	Þingsályktun um framkvæmdaáætlun í málefnum fatlaðs fólks til ársins 2014 [Resolution on a plan of action on disabled people’s affairs to the year 2014]
Ministry of Welfare, 2016	Framkvæmdaáætlun í málefnum fatlaðs fólks 2012-2014. Stöðu- og árangursmat [Plan of action on disabled people’s affairs 2012-2014. Status and impact assessment]

## 6.1 Findings

To begin with, the findings are organized into three sections. The first one focuses on physical accessibility to the built environment in Iceland, and accessibility initiatives in the town of Akureyri. The second section is about public transportation in the Icelandic context, as well as in the town of Akureyri. The last section covers accessible transit

services for disabled people, organization of such services in the town of Akureyri, as well how that service affects occupation. In the last section of this chapter the findings are then synthesised and presented as key concerns. Discussion is intertwined with the presentation of the key concerns.

### 6.1.1 Physical accessibility to the built environment

The newest plan of action regarding disabled people's affairs in Iceland (valid from 2017 – 2021) puts emphasis on universal design, and that such values should guide all organization of the man-made environment (Resolution no. 16/146, 2017). National authorities want to accomplish this by: (1) Increasing the knowledge of the value of universal design for the society, (2) implementing universal design into alteration of the built environment, and (3) ensuring that accessibility issues do not hinder people from participating in society. One of the implementation strategies is to encourage the public sector to appoint officers who will monitor accessibility and make suggestions on how to improve accessibility (Resolution no. 16/146, 2017).

One of the objectives of the Icelandic building code act (Act no. 160/2010) is to ensure accessibility for all people to buildings and their premises. That means that all people should be able to access and use buildings on an equal basis, and should not be discriminated on the basis of impairments or illness. They should be able to enter and exit buildings in a safe manner, including in rare situations such as when building needs to be

evacuated. Furthermore, universal design values should be kept in mind when buildings and their premises are designed.

An institution has been established under the ministry of environment and natural resources called The Iceland Construction Authority, which is in charge of all matters regarding buildings (Act no. 160/2010). When looking into their website ([mannvirkjastofnun.is](http://mannvirkjastofnun.is)), their main emphasis seems to be on safety issues, including electrical, fire and structural safety. However, they also oversee accessibility matters in buildings (Act no. 160/2010). Local authorities employ building inspectors who monitor the design and construction process of all new buildings, as well as significant alteration of older buildings. The Iceland Construction Authority prepares guidelines, procedural policies and inspections checklists to be used by these building inspectors before they issue building permits (Act no. 160/2010). In addition to the building code act, there is a building code regulation with much more detailed information (Regulation no. 112/2012) as well as guidelines from the Iceland Construction Authority with further details on how to implement certain accessibility aspects, for instance regarding entrances or parking spots (Iceland construction authority, n.d.).

Even though the Icelandic building code (Act no. 160/2010; Regulation no. 112/2012) puts emphasis on accessibility for all and universal design in all buildings and their premises, there are loopholes visible both in the building code regulation (Regulation no.



112/2012), as well as documents from the Iceland construction authority, that give people the opportunity to avoid (or at least postpone) compliance with those values.

The first loophole is in the building code regulation (Regulation no. 112/2012) and includes a statement regarding circumstances under which exemption from the universal design requirements is possible. The Iceland construction authority is supposed to prepare guidelines regarding this aspect. The newest plan of action on disabled people's affairs states the importance of making such guidelines, which indicates that they have yet to be written (Resolution no. 16/146, 2017). But while these guidelines do not exist, it is unclear when exemptions are given and when not, and thus it is unclear how applications for such exemptions are processed.

The second loophole lies within the inspection process when new buildings are constructed, or when old ones are altered. The inspection process occurs at three specific times and different accessibility aspects are reviewed at each of these times: (1) before the start of the building process, when the design documents (or blueprints) of the buildings have to be inspected and approved; (2) a safety inspection is conducted when the building has been built, but before it is used; and (3) a final inspection is done within three years after the safety inspection (Regulation no. 112/2012). At all times, an inspection list is used, where the inspector gives comments etc. On these lists, every accessibility aspect has a fixed number for prioritisation, which varies between the

inspection lists. Aspects with number one are only suggestions of things that might be improved, but there is no requirement to do them. Number two means that the issue should be fixed within one year. However, if the person/company is already operating/in business (for example they are changing their buildings or making bigger) there is no deadline for them to fix the issues. If an aspect has the number three, it has to be fixed within one month (Iceland construction authority, 2014).

In the safety inspection (which has to be done before use of the building), all aspects have priority number one or two, never three (Iceland construction authority, 2018a). Thus, lower priorities are given to accessibility prior to occupancy/use of the building, but in the final inspection list some accessibility aspects have number three. These aspects relate to accessible parking spots, entrance of buildings, doorways and hallways, number of elevators, number of accessible washrooms, emergency exits, as well as rooms that are designed specifically with wheelchair users in mind, such as accessible hotel rooms or washrooms. That means that these aspects should always be in good standing within one month from the time the final inspection was done. However, the final inspection list leaves out certain aspects. For example, the number of accessible washrooms gets the priority number three (has to be fixed within one month), however, the interior and the equipment of those washrooms only gets priority number two on that same list.

Another example is that if there are fewer wheelchair accessible seats in a theatre than was shown on the original blueprint, the theatre has one year to fix it (Iceland construction authority, 2018b), except if this theatre was already operating and is altering the building, then there is no deadline for them to fix it (Iceland construction authority, 2014). Interestingly, there is no congruity between the different inspection lists regarding the priority numbering. For instance, the number of wheelchair accessible seats in theatres has a priority number three in the design inspection (Iceland construction authority, 2018c), but two in the final inspection (Iceland construction authority, 2018b). Still the building code regulation (2012) says that aspects that have to do with accessibility should always be finalised before the conduction of the final inspection.

The Icelandic building code is only about buildings and their premises (Act no. 160/2010). However, there are other things that affect accessibility as well, such as physical accessibility on sidewalks and trails, as well as snow clearing. No information was found in legal texts that requires universal design, or good accessibility on sidewalks, trails or streets, except in the building code regarding sidewalks around public buildings, commercial buildings, buildings for elderly, residences for disabled people, student housing, sport facilities and playgrounds that belong to specific buildings (Regulation no. 112/2012). These requirements do cover substantial areas, but not all areas. Additionally, when buildings are older, such as in downtown Akureyri, they are not required to make such changes, unless they apply for a building permit to change something. So, if they do

not intend to do any substantial alterations to the buildings, they are not required to make changes to be accessible. Thus, in order to improve physical accessibility in downtown Akureyri (which is an older area), it has to be the will of building owners to make changes to buildings' entrances, as well as local authorities to make changes for accessibility on sidewalks, streets, parking spots etc. Even though buildings in newer neighbourhoods (built after January 2011) are required to have accessible premises (Act no. 160/2010), there seems to be no requirements for local authorities to have accessible sidewalks. Consequently, both in established areas as well as new areas, there is no requirements to make sidewalks accessible. Still as can be seen in the main land use plan for Akureyri, local authorities do put emphasis on having sidewalks, trails, outdoor recreational areas, cultural institutions and public transportation accessible for all people (Town of Akureyri, 2018b).

Local authorities are responsible for clearing snow and ice off streets and sidewalks in Akureyri (Town of Akureyri, 2018c.). Residents in Akureyri have complained that sidewalks and trails within the town need to be cleared better of snow and ice (University of Akureyri research centre, 2017). However, limited information was found on that topic on the municipal's website and documents. Thus, this topic will not be explored further in this chapter. Still it is important to remember that participants in phase one of this research highlighted this aspect as significant for people with mobility impairments when it comes to moving around in their community (Jónasdóttir, Egilson & Polgar, 2018).

### 6.1.1.1 Accessibility initiatives in Akureyri

In Akureyri there is a joint committee, organized by local authorities and an organization of disabled people, that focuses on contextual factors that shape people's mobility. This committee's main focus is on physical accessibility and will thus hereafter be called the accessibility committee. Their main tasks are to (1) propose how accessibility can be improved; (2) monitor that buildings, sidewalks, trails and parking lots are designed and built according to codes on accessibility, (3) assess accessibility in public buildings and other man-made structures in town and suggest how accessibility can be improved (Town of Akureyri, 2012b). When local authorities are designing new buildings, they should seek comments from this joint committee before final decisions are made.

The minutes of this committee's meetings provide information on frequency of meetings and issues they are working on. Based on the available records of these meetings, this committee has been active since the year 2000. They have had 63 meetings in those 18 years, on average 3,5 meetings each year. However, they seem to have been more active in the beginning, and last year there was only one meeting (Town of Akureyri, n.d.a). The reason for this change is unclear.

The committee has been working towards better access to both buildings and outdoor areas. Some of the tasks they have been working towards are: (1) increasing numbers, or improving quality, of parking spots (downtown, by schools, daycare facilities,

community centres, sport facilities, swimming pools, town hall, and other office buildings); (2) increase the number of traffic lights with sound; (3) improve accessibility on sidewalks, trails, plazas, and other outdoor areas, by adding ramps/slopes, and tending to location of benches and traffic signs; (4) reviewing and commenting on design of local authorities' properties, as well as other buildings (new and old, such as hotel, restaurant, stores, museum, gas station and more); and (5) raise awareness of the importance of accessibility and how it affects daily life of people (Town of Akureyri, n.d.a).

Every year the committee awards companies/buildings for being accessible and report it to media, which is a valuable initiative to raise accessibility awareness in the community. Venues that have received awards include the House of Culture, the airport, a hotel, three restaurants, several stores, two banks, a daycare facility, a mall, a car dealership, and a bakery (Town of Akureyri, n.d.a). Furthermore, they raise awareness by contacting certain institutions or organizations to discuss with them accessibility issues those institutions or organizations may be able to affect.

In the old plan of action, the intention was that every municipality would assess accessibility in their area (Resolution no. 43/140, 2012). However, even though Akureyri has been ahead with monitoring by establishing their accessibility committee, they have only formally assessed accessibility to the public bus system, but not to the built environment. The committee intended to cooperate with the occupational therapy

department at the University of Akureyri to do a formal assessment of public buildings in the years 2002-2003, but for an unknown reason, that cooperation fell through. Also, information was found regarding a report on assessment of public buildings made in 2005, which was conducted by two wheelchair users, but the actual report could not be found on the Akureyri website. A request was sent to local authorities to access this report, but the response received indicated that the report is not available because it was never finished (Einarsdóttir, personal communication, March 12th, 2018). The reasons for this lack of assessment are unclear. No indications of requirement for accessibility assessment is in the new plan of action, however as mentioned above the government is encouraging the public sector to appoint accessibility officers to monitor accessibility in their workplaces (Resolution no. 16/146, 2017).

Nevertheless, the welfare policy draft from local authorities in Akureyri, states that they intend to be exemplary when it comes to accessibility. According to that policy draft, they intend to assess accessibility in their buildings, as well as consider the organisation of the downtown area (Town of Akureyri, n.d.b). They further suggest involving users in those assessments. No evidence was found on whether this policy has been approved by local authority's administration yet.

### 6.1.2 Public transportation in the Icelandic context

Interestingly, there seems to be a contradiction on the right of disabled people in Iceland when it comes to public transportation. Based on the 19<sup>th</sup> article in the Act on onshore passenger transportation and freight transport (Act no. 28/2017), it is prohibited to reject a passenger to book a trip or to enter a bus, because of an impairment or disability.

However, another clause says that it is not prohibited if it is a matter of safety requirement, or if it is physically impossible for the person to use the transportation service, due to the design of the vehicle or bus stop. The policy gives the transportation system an out in terms of providing accessible service, as the provision of accessible public transportation is dependent on the will of the providers of this service. On top of that, other acts state that disabled people who cannot use public transportation have the right to receive an accessible transit service (Act no. 59/1992; Act no. 37/2018). Thus, based on this information, everyone has the right to use public transportation, except when society fails to provide proper accessible vehicles, then people can get a special transit services, segregated from non-disabled people.

One of the sub-objectives of the newest policy and plan of action for disabled people's affairs in Iceland is to increase opportunities for disabled people to use public transportation, both in rural and urban areas (Resolution no. 16/146, 2017); a similar objective was in the older policy (Resolution no. 43/140, 2012). Despite the stated



intention of checking the proportion of satisfied users when measuring if the goal of the previous policy was met, in reality the government did not seek users' feedback. Instead they sent an inquiry to the public bus company in Reykjavík requesting information about its current status, such as the proportion of major routes that are accessible for people with mobility impairments. Furthermore, from the information provided in the report, it looks like the committee doing this evaluation ignored asking about public transportation in other parts of the country such as Akureyri (Ministry of Welfare, 2016). For the current policy, authorities intend to assess if their goal will be met by checking the proportion of buses that are accessible in the year 2021, even though it is unclear what proportion they are aiming at (Resolution no. 16/146, 2017). Again, there seems to be limited intention to include users in that assessment.

In the year 2017, Icelandic authorities agreed to put into effect a regulation from the European Union (EU) on rights of bus passengers (Regulation no. 475/2017; Regulation no. 181/2011). This EU regulation covers aspects that are important for disabled people, such as accessibility, assistance, and training of employees that may affect their ability to provide useful assistance. However, this regulation only covers bus trips that are at least 250 kilometers and does thus not cover bus trips within a town, nor shorter trips to nearby locations. No legal requirements were found that would cover those shorter trips, as the act on onshore passengers' transportation and freight transport (2017) only refers to this EU regulation on the matter. Whether any such document does exist or not is unclear; it

was not located through the search strategy of this study. However, the Ministry of Interior indicated in a letter they sent to the association of disabled people, that local authorities should be responsible for covering transportation services for disabled people in their areas, and thus local authorities can decide if they will provide public transportation or accessible transit services for the group (Sjálfsbjörg, 2017).

According to the EU regulation on rights of bus passengers, when decisions are made regarding renewal of vehicles, and design of new transportation centres and bus stops, the needs of people with mobility impairments should be taken into consideration (Regulation no. 181/2011). However, the vague language used in the regulation gives the power again to the service providers, creating a disclaimer which gives the companies more freedom to do what works best for them. For example, managers should *try to* [emphasis added] consider the needs of people with mobility impairments as based on design for all. Similarly, when decisions are made regarding update of vehicles, transportation companies should *when possible* [emphasis added] respect the needs of this group (Regulation no. 181/2011). It is striking that the current and relatively new legislation regarding public transportation (longer trips), (Act no. 28/2017) does not put more emphasis, and stricter requirements regarding accessibility to vehicles and bus stations.

On these longer trips, transportation companies are required to provide disabled people with the assistance or support they need, if the transportation company is informed about these needs at least 36 hours in advance. However, the regulation also says that even if people do not inform about their needs for assistance in advance, the company should still do everything in their power to assist the person with a mobility impairment to enter or leave buses (Regulation no. 181/2011). Furthermore, the companies are required to establish that their bus drivers, or people assisting disabled people, will get training or at least have some guidelines including information that relates to disability, impairments, what kind of assistance people may need, as well as various hindrances people are dealing with such as attitudes, accessibility issues, and organizational hindrances (Regulation no. 181/2011). However, as with the accessibility requirements, these obligations only apply for longer bus trips.

Even though there are certain requirements in Icelandic legislation regarding how the companies should facilitate use of the public transportation for longer trips by disabled people, little information was found on how and whether there is any active monitoring of those services. Interestingly, it has been pointed out that the lines of responsibility between different governmental agencies (Iceland transport authority and the Icelandic road and coastal administration) seem to be blurred, as each expects the other to assume responsibility (Sjálfsbjörg, 2017). When the lines are blurred, it gives the governmental agencies a way out of addressing those accessibility issues in the bus system.

According to the Act on onshore passengers' transportation and freight transport (2017) the Icelandic transport authority (Samgöngustofa) is responsible for monitoring if the operation of transportation companies functions in accordance with laws and regulation. When looking up the responsibility of the Icelandic road and coastal administration it can be seen that they are responsible for taking care of tendering processes, negotiations and monitoring of service contracts for public transportation paid by the government (Act no. 120/2012). However, it seems like they have nothing to do with other public transportation services that are privately owned. In addition, this same Act does not say anything about accessibility to public transportation, or any services for disabled people. Those issues are only mentioned in the act on onshore passengers' transportation and freight transport, which identifies the Icelandic transport authority (Samgöngustofa) as responsible for monitoring such things (Act no. 28/2017).

#### 6.1.2.1 Public transportation in the town of Akureyri

Strætisvagnar Akureyrar (SVA), a division of local authorities, is responsible for public transportation services in Akureyri, and operates six different fixed bus routes within the town that are free of charge for users (Town of Akureyri, 2018; Akureyrarstofa, 2018). The opening hours of the public buses are from 6:25 – 23:03 on week days (Town of Akureyri, 2018). One route operates on weekends between 12:18 – 18:18 (Akureyrarstofa, 2018). Users of the buses have pointed out the need for extending the

opening hours of the public buses, by offering more services on weekends and later in the evenings (University of Akureyri – research centre, 2017).

Local authorities received funding from the Ministry of Welfare to do an assessment of the accessibility of public buses and bus stops in Akureyri, which was executed in the fall of 2015 (Town of Akureyri, 2016a; Town of Akureyri, n.d.c). The Akureyri main bus station was not accessible, but local authorities intended to build a new transportation centre in the year 2017. According to local authorities' newest policy this centre should be built before the end of 2018 (Town of Akureyri, 2017b). Still, the construction had not started in February 2018, and one of the reasons was that a proper location had not been found yet (Viðarsson, 2018).

Based on the assessment report, all public buses in Akureyri are accessible as they have a ramp by the back entrance, and do not have any steps. Out of the total of 119 bus stops in town, only 14 of them were not accessible and needed to be improved (Town of Akureyri, n.d.c). Based on this information, the physical accessibility of all buses and the majority of the bus stops is in good status. However, the assessment only looked at physical accessibility at the actual bus stops, not usability for people with mobility impairments, or how effective the public transportation is for this group in Akureyri. Furthermore, it seems like users were not included in this assessment, and thus they were not asked about factors that may affect the usability such as the way drivers park the

buses at bus stops, snow clearance at bus stops, how accessible it is to get to the bus stop, attitudes of drivers and other passengers etc.; issues that were identified by service users in the first part of this study (Jónasdóttir, Egilson & Polgar, 2018).

Improvements have been made in recent years regarding accessibility to public buses in Akureyri. This can be seen from a record from a meeting of the accessibility committee in Akureyri. In the year 2012 (three years before the assessment) the committee requested that all public buses in Akureyri should be accessible for all people, and that information about accessibility should be available on the municipality's website (Town of Akureyri, 2012a). This information from the accessibility committee indicates that not all buses were accessible in the year 2012, but according to the assessment they were accessible in 2015 (Town of Akureyri, n.d.c). However, no information can be found on the websites of local authorities regarding if the buses are accessible or not, and thus users would have to seek such information through different means.

### **6.1.3 Accessible transit services for disabled people**

Local authorities are responsible for organizing and providing accessible transit services for disabled people in Iceland (Act no. 59/1992; Act no. 37/2018). A clause on such transit services was in the act on disabled people's affairs (Act no. 59/1992), but with the recent change in legislation, this clause has now been added to the new version of the act

on Social services provided by local authorities, which took effect on October 1<sup>st</sup>, 2018 (Act no. 37/2018).

Local authorities set their own policy regarding the transit services they provide; however, it should be based on guidelines established by National authorities (Act no. 59/1992; Ministry of Welfare, 2012; Act no. 37/2018). The current guidelines available from national authorities are from 2012; newer version of the guidelines, based on the recent change of laws, have not been established yet. The new version should be done in liaison with the association of local authorities and representative organization of disabled people (Act no. 37/2018). Local authorities in Akureyri have established their own policy, which at least partially match the guidelines available (Town of Akureyri, 2010).

The department of residence (Búsetudeild), which provides services for disabled people to support them to live and participate in society, is responsible for processing applications for the transit service. However, the public transportation department (SVA), is responsible for the operation of the service. These two entities are then supposed to have collaborative meetings regarding their collaboration, work procedures and implementation of the service (Town of Akureyri, 2010). No evidence was found on such meetings.

### 6.1.3.1 Organization of the transit service in Akureyri

According to the transit service policy in Akureyri, the service is for people who are legal residents in the town of Akureyri and cannot use the public transportation, nor a private vehicle due to long-term impairment, which lasts at least three months. Individuals who are dealing with bone fractures, joint replacements or other short-term impairments are not provided with transit service, except if they are only receiving pension payments from the social insurance of Iceland, are socially isolated and do not have a family support net (Town of Akureyri, 2010). Interestingly, in the new act on social services provided by local authorities (Act no. 37/2018), it states that disabled people who cannot use public transportation have the right of getting transit service. However, in that act there is no definition of what it means to be disabled. An absence of a definition may give the community a way to limit who has access to the service as they will have to decide who is eligible or not.

Unfortunately, no information can be found on how many individuals currently use the transit service, but in 2013 there were 94 users, including both children and adults (Town of Akureyri, 2013b). In the year 2016, the transit service operated five vehicles (Town of Akureyri, 2017a). Before 2012 the service had three vehicles but got a new one in the year 2012 and another one in year 2014 (Town of Akureyri, 2013a; 2015). It seems as if



all of them are available during the day, but only one vehicle in the evening (Town of Akureyri, 2014).

The transit service covers the same area as the public buses within the town of Akureyri, as well as trips to Kristnes, a rehabilitation center 10 kilometers south of the town (Town of Akureyri, 2010). Interestingly, there seems not to be any such service provided in areas that are still part of the municipality of Akureyri, but are located outside the town, such as the islands, Hrísey and Grímsey. This fact raises questions about the options disabled people have in those areas, as they have the right of services from local authorities in Akureyri (Act no. 59/1992; Act no. 37/2018; Town of Akureyri, 2010).

The transit service is free for users, and if individuals cannot be without an assistant, the assistant can join the user in the trip for free as well. However, if the users need to go to the Kristnes rehabilitations center, they may be charged for that trip (Town of Akureyri, 2010). Still, no information is available on if they do charge for those trips, or how much it is.

According to the policy in Akureyri, the service is operated from 7:30am to 11:30pm on weekdays (Town of Akureyri, 2010). However, in reality the service does not operate after 11pm on those days, as that is the operation times for the public buses as well (Town of Akureyri, 2018). Trips that users need on a regular basis, for example to go to

work or school are negotiated and planned beforehand. On the other hand, any irregular trips have to be requested one day in advance, or before 3pm the day before. (Town of Akureyri, 2010). However, in the newest changes that have been made on the laws regarding accessible transit services, the government added a sentence which is based on article 20 of the CRPD, stating that disabled people should be able to go anywhere they need, “in the manner and at the time of their choice, and at affordable cost“ (United Nations, 2006, p.14; Act no. 37/2018, p.5). This clause will require considerable increase of service and cost associated with it. This increase in cost seems to be causing some authorities at local level concerns (Parliament, 2018; Welfare committee, 2018), as funding from national authorities will need to be increased accordingly.

Currently, no transit service is offered on weekends and holidays, which leaves only the option of using a taxi. Outside of the operation time of the transit service, users can use a coupon, provided by local authorities, as a subsidy to pay for a taxi (Town of Akureyri, 2010). Interestingly, there is no information on the value of these coupons, nor how many coupons users get. Additionally, the information provided in the policy about when these coupons are valid is conflicting, and hard to understand. In article five it says that these coupons can be used on weekends and other holidays. However, in this same article, it states that the coupons are valid during the operation time of the public buses (Town of Akureyri, 2010). Based on that, users are supposed to be able to get subsidised taxi during the public bus operation time on weekends and holidays, which seems to be

limited to the time between 12:18 – 18:18 on weekends (Akureyrarstofa, 2018; SVA, 2016). No information was found on how it works on holidays.

Local authorities in Akureyri conducted a survey in the year 2013 with the objective of assessing how satisfied or dissatisfied the users of the transit service were. Their conclusion was that most of the participants were very or rather satisfied with every aspect of the service and the areas they intended to improve were related to safety in the cars, such as use of safety belts, and education for the drivers about safety issues (Town of Akureyri, 2013b). As this conclusion is not in line with the experience of participants in the first phase of this research, the survey report was read with that in mind. What was striking is that the findings in the survey were simply interpreted in a “positive” or “best” way for local authorities, and indeed was conducted by local authorities. An example of this is that they (as most other people would also do) put emphasis on the 88% of participants who said that always or most of the time the cars are on time. However, if the intention is to improve services, it is important to consider also why some participants say that the cars are only sometimes on time. Additionally, written comments that participants gave were not highlighted as issues that need to be improved. Even though there were important questions asked in this survey, additional questions were needed that would help local authorities to figure out ways to improve the service. Such question could include: how can the service be improved? Or how can we better accommodate users’ needs?

### 6.1.3.2 Transit services and occupation

According to Icelandic legal texts (Act no. 59/1992; Act no. 37/2018), disabled people have the right to get transit service to enable them to engage in work and education, enjoy leisure activities, and go to service institutions or other services they need. In local authorities' policy, they similarly mention work, study and leisure activities, but the policy is worded more specifically when it comes to services as they talk specifically about health care, rehabilitation, and training. However, users are limited to 20 trips a month for purposes other than work, training, health care and rehabilitation. Additionally, there is an overall limit, as trips for any use should not exceed 70 a month in total. One trip is defined as trip from A to B, but not back and forth (Town of Akureyri, 2010). That means that to go somewhere and back home, the user spends 2 trips out of the limit of 70. That also means that people only can go 10 times a month to do leisure activities. Yet, another example of mismatch between documents, the application form for the service specifies different number of trips (Town of Akureyri – department of residence, 2017, p.1). This mismatch of information makes it confusing to know which information is valid and which is not. However, even though presumably the policy supersedes the application form, the interpretation of these documents by the person processing the application is what will shape the outcome for the applicant. None of the documents defines what leisure or recreation means. It could be limited to only organized activities

such as participating in some sports once or twice per week, but in much broader sense, it could include visits to family or friends, going to the pub etc.

Interestingly, the guidelines from the ministry adds in the component of choice, as disabled people should be able to engage in work, study, leisure and recreation activities that they have chosen to do (Ministry of Welfare, 2012). It further states that the number of trips should be according to the activities the individuals engage in, as well as their needs and goals. The way this document extends the definition of the occupations in which people have the right to engage is not reflected in the Akureyri policy (Town of Akureyri, 2010). What is also interesting is that the values that can be identified in the guidelines have not transferred into the policy, which would make sense if the guidelines were brand new. However, this text is from the year 2012 and according to it, the policy of local authorities shall be revised and updated at least every two years. This information raised the question whether the policy on transit service in Akureyri has been updated, and if there is a newer version than the one that can be found on their website (Town of Akureyri, 2010), which is from the year 2010. An inquiry was sent to the town of Akureyri regarding if there is a newer version available. Unfortunately, no response was received. However, now with the recent changes in legislation, local authorities in Akureyri will have to review their policy.

There is a precedent that shows that users can access the transit services solely for leisure purposes of their choice. Based on a conclusion from the Althing ombudsman, a decision that was made by unidentified local authorities in Iceland regarding transit service for a disabled woman was considered against the law. The case was that the woman was denied transit service to her chosen leisure activities, she could only get the service to go to specific organized activities (decided by local authorities) (Althing ombudsman, case no. 9160/2016). Based on this conclusion, the law should be interpreted in a broad sense when it comes to defining what leisure or recreation means in a newer version of the policy. Unfortunately, the woman passed away before conclusion was reached in her case. However, her relatives recently received a settlement from the municipality (Ólafsdóttir, 2018). Furthermore, the Althing ombudsman highlighted to the Ministry of Welfare the importance of having clearer base regarding the rights of people to get transit service in the relevant act (Althing ombudsman, case no. 9160/2016).

In the current municipal policy, there is also no focus on being able to go somewhere spontaneously, as the service has to be ordered before 3:30pm the day before. One would think that a disabled person could request a taxi and use one of the coupons to subsidise the cost, but as the coupons are only valid during limited time on weekends (if the former information is correctly understood), it does not help with the spontaneous activities, except on Saturday and Sunday afternoons.

Based on a survey that was sent to all users of the transit service in the year 2013, 65% of participants consider that most of the time, or sometimes it is easy to order the service 24 hours in advance. However, 18% experience some difficulties with this in more than 50% of the instances, and 18% did not answer the question. Participants also added written comments where they expressed the need for having service on weekends and later in evenings, as well as wanting to be able to order the service the same day (Town of Akureyri, 2013b).

The guidelines on transit services from the national authorities (Ministry of Welfare, 2012) seem to have much more focus on user's involvement which aligns closer to the CRPD than other policy documents related to this service area. In the guidelines it says that both the design and implementation of the municipality's policy on transit service has to be consistent with international commitments that the Icelandic government has recognised such as the CRPD. The guidelines emphasise involvement of users, or their representatives in decision making such as regarding number of trips they need etc. (Ministry of Welfare, 2012). That document further says that the implementation of transit services shall promote disabled people to have control over their own situation and their life, as well as support their self-respect and quality of life. Every individual's situation has to be assessed, such as their goals and needs for transit service to support those goals (Ministry of Welfare, 2012). Finally, with the recent changes in legislation, there is more focus towards the CRPD by stating that people should be able to go where

they need and want to go, in the manner they choose and at the time of their choice and at affordable cost (Act no. 37/2018).

Local authorities in Akureyri did introduce a draft of new welfare policy for the years 2017-2021 in the year 2016 (Town of Akureyri, 2016b). However, no information can be found whether this policy ever came into effect. Still, the document gives some clues on the intention of local authorities, their values and perspectives of certain service areas. According to this document, their intention is to improve the transit service and ensure that people can go between places on evenings and weekends, and to reconsider cooperation (and subsidy) with taxis so people will certainly get service outside of the operation hours of the transit service (Town of Akureyri, 2016b).

One of the objectives of the government's policy and plan of action, which was valid from the year 2012-2016, was that disabled people should be offered a transit service, so they can be active participants in daily life. To achieve this, each service area (or municipality, including Akureyri) was supposed to design and present a plan of action regarding their service and develop new ways to meet the needs of users (Resolution no. 43/140, 2012). Local authorities in Akureyri, made a cost estimate for improvements on their service, based on results from a survey from 2013 which was conducted to check how satisfied their users were. Unfortunately, a budget to be able to implement those changes was not obtained (Ministry of Welfare, 2016).



## 6.2 Synthesis of findings and discussion

This paper has scrutinized the public policies and legal texts that have to do with public transportation, accessible transit services and physical accessibility in Iceland, more specifically in Akureyri. The findings show that even though moving slowly in the right direction, the Icelandic society is far from being inclusive, it is still full of barriers to public transportation, transit services and accessibility, which creates disability and violates people's fundamental rights to being able to move around their community.

It is clear from the findings that many issues need to be fixed to fully ensure disabled people's rights. Legal texts read for this study do state the rights of people for public transportation, transit services and accessible environment. Still, in all cases there are some exemptions or some clauses that diminish the former statements and give other people the power to interpret and implement those texts in a way that does not fulfill disabled people's fundamental rights. For example, the motivation to create fully accessible public buses may be limited because of the existence of legislation that provides for special transit services for disabled people. Also, buildings should be accessible, but exemptions to that requirements are granted, and renovations can be postponed.

In order to improve the protection, promotion and fulfillment of the rights of disabled people, the Icelandic government will have to address some key concerns that the findings of this study highlighted. The following discussion is organized around those concerns: (1) limited users' involvement in policy making; (2) inconclusive or incomplete information; (3) Poor clarity in legislation and guidelines; (4) Insufficient monitoring of services; and (5) limited fit with occupational right and justice values. Even though the new legislation in Iceland seems to address some of those concerns, time will have to reveal if that legislation translates successfully into practice, or if they are hollow promises.

### 6.2.1 Limited users' involvement in policy making

One highly important issue that needs to be addressed is the limited involvement of users' at the policy level. Disabled people should be actively involved in developing and making decisions regarding policies and programs concerning them (United Nations, 2006). When reading the documents included in this study, it was often hard to see if and how much the voices of service users or disabled people were incorporated into them. However, in some instances it was clear that users were not involved in a policy process, such as when authorities only asked the bus company about their accessibility but did not ask users. This fact raises questions regarding whether the voices of users can really be seen in Icelandic policy documents, or how much they are involved in the policy process.

According to Löve, Traustadóttir and Rice (2018) disabled people are not sufficiently involved in policymaking processes in Iceland, as required by the CRPD. Often, they are brought too late into the process when decision have already been made, or their suggestions have been ignored, which limits their effect on the policy outcome. In line with the CRPD, it is crucial that users are involved in the policy development both at national and local level, as the newest changes in legislation puts emphasis on (Act. no. 38/2018; United Nations, 2006). This change in legislation will hopefully lead to more voices of disabled people in the Icelandic policy development.

### 6.2.2 Inconclusive or incomplete information

A characteristic of the data search and analysis in this study was limited information, and disconnect between sources in all three service areas, which makes it hard to know if the information found is accurate. Different documents contradict each other in some cases which makes it hard to understand the overall policy. When it is hard to know which information is valid, and which is not, it must be hard for users to find the information they need and can rely on. Furthermore, such contradiction makes it hard for people to know their rights for services, such as regarding what they can use their transit service trips for. Authorities, both at local and national level will have to ensure that there is coherence in the chain of policy documents in all service areas.

In addition to contradicting information in policy documents, basic information about services was not accessible, or even available. One example is that users should be able to access information regarding which public buses are accessible on companies' websites or through other simple means. Thus, such information will have to be provided, both for local buses, as well as buses that provide longer trips. Another example is that it is hard to find appropriate information regarding the transit service in Akureyri, such as for what kind of trips users can use the service for, when users can use a coupon and what is the value of the coupons. This lack of information also raises the question of whether the service providers and staff members of local authorities do have the correct information to base their services on. The need for having accessible information for disabled people regarding services is emphasised in article 4 (h) of the CRPD (United Nations, 2006)

### 6.2.3 Little clarity in legislation and guidelines

The current policies and practices in all three service areas in Iceland are not congruent with the CRPD, as they allow for various interpretations, which gives the society alternatives to offer services not in line with the convention. Thus, there is a need for clear and comprehensive policies and following are recommendations for all those service areas.

### 6.2.3.1 Physical accessibility in the built environment.

The findings show that in Iceland, most emphasis is on accessibility when buildings are designed, but not necessarily in the later construction stages. For example, the accessibility committee looks at blueprints at the design level; the design inspection, conducted by the inspector from local authorities, is the stage in the inspection process that puts most emphasis on accessibility. This indicates that in order to ensure sufficient attention to accessibility, higher priority should be on accessibility in later stages of the construction process, that is in the safety and final inspection. Higher priority in those stages would mean that issues should be fixed right away. In order for authorities to be consistent with the universal design emphasis in their building code (Act no. 160/2010; Regulation no. 112/2012), such a change in their policies and practices is critical.

Additionally, the emphasis in the newest plan of action (Resolution no. 16/146, 2017) on how to avoid fulfilling people's rights by getting exemption from the universal design values, challenges the integrity of universal design values in Icelandic policy, as this is a policy document that is supposed to support disabled people's rights. Still, if any exemptions are to be given, clear and strict guidelines will have to be written. Based on article nine of the CRPD state parties shall "develop, promulgate and monitor the implementation of minimum standards and guidelines for the accessibility of facilities and services open or provided to the public" (United Nations, 2006, p.9). Thus, it might

be beneficial if Icelandic authorities established specific document that synthesise all legal requirements concerning accessibility in the country as well as regulations and guidelines affecting it, perhaps something similar to the Accessibility for Ontarians with Disabilities Act (2005). That way, Iceland would have a separate document which could serve to assist in construction processes, as well as to raise awareness of service providers and the general public. Putting together such documents would also show that the government honestly respects the universal design values and different needs of people when it comes to accessibility. Such a document would also have to include other locations than just buildings and their premises, such as trails, sidewalks etc. Additionally, it would be beneficial if such a document would raise awareness of other aspects that affect accessibility such as snow clearing, obstacles on pavements, the way people park their cars etc., as these aspects have been identified by disabled people as influential on their accessibility (Jónasdóttir, Egilson & Polgar, 2018; Malhotra & Rowe, 2014; Ripat, Brown & Ethans, 2015).

#### 6.2.3.2 Public transportation.

There is no question that article nine in the CRPD requires that all people have access to both bus services and facilities (United Nations 2006). Thus, the Icelandic legislation should cover all bus trips, not only the longer ones. Additionally, detailed guidelines or standards on how to implement the requirement of the law should be established, as well

as a mechanism to monitor the implementation, and enforce it (United Nations, 2006). Furthermore, the inconclusive and flexible ways to interpret the wording in current acts and regulations, are not according to the CRPD and have to be reconsidered.

### 6.2.3.3 Accessible transit services.

The new legislation in Iceland (Act no. 37/2018) adds important aspects from the CRPD into the policy field and the need for reviewing and clarifying the policy regarding accessible transit services is especially important. Currently, local authorities make their own policy regarding transit services, which should be based on guidelines from national authorities. However, these guidelines are very open, which allows for various interpretation; local authorities will need a clear base to build their services on. Thus, in order to better support disabled people's rights for the services, perhaps national authorities should make one set of regulations that will cover transit services for the whole country, or at least have clearer guidelines. Such regulation or guidelines would have to incorporate the aspects that were added to the new legislation, such as regarding the importance of users having choice of where they go, when, and at an affordable cost (United Nations, 2006). However, if that is to be done, financial resources would have to follow for local authorities to be able to implement it.

#### 6.2.4 Insufficient monitoring of services

“States Parties shall, in accordance with their legal and administrative systems, maintain, strengthen, designate or establish within the State Party, a framework, including one or more independent mechanisms, as appropriate, to promote, protect and monitor implementation of the present Convention” (United Nations, 2006, p. 25). Limited information can be found on whether such a framework has been or is going to be established in Iceland. However, there is evidence of efforts to monitor compliance with the rights of disabled people; mainly as it relates to physical accessibility.

Some of those efforts are in their infancy, such as the encouragement of authorities to appoint accessibility officers within the public sector (Resolution no. 16/146, 2017). Other efforts have been in place for a while; that is the accessibility committee in Akureyri (Town of Akureyri, n.d.a), as well as the building inspections (Regulation no. 112/2012). However, it is unclear how efficient these efforts are when it comes to enforce the changes needed. Additionally, lines between responsibility of different governmental agencies seem blurry when it comes to monitoring of the public bus system and need to be clarified.

Even though some disabled people are involved in the accessibility committee in Akureyri, no requirements seem to exist to involve disabled people in the other monitoring efforts. Still, it can be argued that disabled people should be involved in all



the inspection stages of the built environment. The reason is that even though the building inspectors have the facts on certain aspects that relate to accessibility such as number of elevators, door width and inclination of a ramp, in most cases, they do not have the experience of needing proper accessibility to be able to move around and thus may not see issues that an experienced wheelchair user might see.

#### 6.2.5 Limited fit with occupational right and justice values

Both public transportation as well as transit services shape the occupational opportunities people have (Jónasdóttir, Egilson & Polgar, 2018; Bascom & Christensen, 2017). Based on the findings from this study, the occupations that are most at risk are leisure and recreational occupations, spontaneous occupations, as well as any occupations on evenings and weekends. The reasons being that those services are limited during weekends and evenings, and thus any occupations during those times are difficult to attend. The transit service has to be ordered the day before, making it impossible for a user to make spontaneous decisions regarding occupations. Additionally, the vague (or missing) definitions of leisure or recreation make it hard for people to know for what purpose they can use the service. Not only are these limitations conflicting with the CRPD (United Nations, 2006), but they also violate peoples' occupational rights, or the human rights of people to participate in occupation (Hammell & Iwama, 2012; Hammell, 2015).

Some of the policy documents, such as the guidelines from national authorities regarding transit services incorporate values that align somewhat with occupational right and justice perspectives, and even more so have such values been incorporated in the new legislations (Act no. 37/2018; Ministry of Welfare, 2012). This is an excellent change and a recognition of the rights of disabled people. However, those values cannot yet be seen in policies at the local level, nor in basic information about the services, indicating they have not yet been implemented into services. Based on the newest legislation, national authorities are required to publish new guidelines, and local authorities review and update their policy, which will have to embrace such human right values regarding occupation.

### 6.3 Summary

In this chapter findings of deductive content analysis of publicly available policy documents from national and local authorities in Iceland were presented. Those findings were organized into three sections in relation to accessibility to the built environment, public transportation, and accessible transit services for disabled people. There were certain common concerns between those service areas that were highlighted in a synthesis and discussion of the findings, that is: (1) limited users' involvement in policy making; (2) inconclusive or incomplete information; (3) Poor clarity in legislation and guidelines; (4) Insufficient monitoring of services; and (5) limited fit with occupational right and justice values.

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## Chapter 7

### 7 Synthesis and discussion

In this final chapter, a brief summary of the two research phases is provided, as well as discussion of the synthesis of the main findings from both phases. Specifically, I discuss four aspects identified as being common between the two research phases, that is: (1) User's involvement in policy development; (2) Clarity and consistency of policy texts; (3) Monitoring of the system as a whole; and (4) Occupational rights and justice values in policies. Furthermore, I discuss the implications of this PhD work for occupational science, service users, policy makers, and service providers. Following, limitations of the study are highlighted as well as suggestion for future studies and concluding remarks.

#### 7.1 Summary of the research phases

This research journey started with a broad question about what was known in the literature about how services, systems and policies affect community mobility of mobility device users. To answer this question a scoping review was conducted which summarized information on barriers and facilitators to community mobility of people who use mobility devices that are created by services, systems and policies. The findings indicated that services, systems and policies have gained limited attention in the literature in relation to community mobility. Still the limited information available suggested a few



services, systems and policy aspects within that realm that shape community mobility, mainly transportation, open-space planning, and architecture and construction (Jónasdóttir & Polgar, 2018).

The findings of the scoping review led to my interest in gaining a deeper understanding on how services, systems and policies can restrict or support community mobility for people with mobility impairments. This question was addressed in the first phase of this exploratory case study (Jónasdóttir, Egilson & Polgar, 2018), which included focus group interviews with people with mobility impairments in the town of Akureyri, Iceland, and service providers in the same area. The findings highlighted five critical aspects that could help support community mobility for people with mobility impairments, if incorporated into policy implementation:

- 1) Being mobile: A key to meaningful occupations** - Being able to move around the community increases the opportunities people have to engage in meaningful occupations and participate in society.
- 2) Users as agents in their own lives** - People with mobility impairments want to have control over their own lives. They want their voices to be heard and be actively involved in development of policy implementation.

- 3) **Means of transportation** - People with mobility impairments need to have accessible, flexible and affordable means of transportation to improve their chances of community mobility at the time and place of their choice.
- 4) **Accessibility awareness** - Awareness regarding the importance of accessibility to the physical environment is needed, in order for the society to understand how accessibility can be improved.
- 5) **Integration of services and systems** - In order to improve the system, it has to be looked at holistically as services have to be integrated and work together in order to support community mobility.

The focus group findings raised the following questions: How do legal texts, policies, and other public documents from national and local authorities depict services affecting physical accessibility, and transportation services for disabled people in the town of Akureyri, Iceland? Publicly available documents that were found on official websites of national and local authorities for each service area were reviewed and analysed using deductive content analysis and applying an occupational perspective. The findings were mainly organized by the specific policy areas targeted, that is accessibility to the built environment, public transportation, and accessible transit services. The key concerns

raised in chapter six that were common between the different policy areas are the following:

- 1) **Limited users' involvement in policy making** - The findings strongly indicated that disabled people are not involved in policy development concerning them in Iceland as they should.
- 2) **Inconclusive or incomplete information** - A common feature found during this document review was limited and contradicting information between documents, which made it hard to know which information were valid.
- 3) **Little clarity in legislation and guidelines** - Due to little clarity in policy documents, various interpretations are possible, which gives the power to service providers regarding how those policies translate into practice.
- 4) **Insufficient monitoring of services** - The findings indicated that there are some efforts for monitoring of services within the Icelandic system, primarily in relation to accessibility. Still, there is no evidence of a centralised monitoring of the rights of disabled people, and it is unclear how effective the existing efforts are.

- 5) **Limited fit with occupational right and justice values** - Certain occupations are at risk for people with mobility impairments, such as leisure and recreational activities, as well as spontaneous activities, and activities that take place on weekends and evenings. Furthermore, even though more values that align with occupational right and justice can be seen in newer policy documents, those values cannot be seen in documents which guide the implementation at the local level.

## 7.2 Synthesis of the overall case

The main findings from both phases were compared and synthesised. This synthesis led to identification of the following common and compatible key areas (see table 13), which guide the discussion regarding recommendations for policy development in Iceland.

**Table 13: Synthesis of the overall case**

Key areas	Recommendation	Main findings	
		Phase 1	Phase 2
1	<b>Users' involvement in policy development</b>	- Users as agents in their own lives	- Limited users' involvement in policy making
2	<b>Clarity and consistency of policy texts</b>	- Accessibility awareness - Means of transportation	- Inconclusive or incomplete information - Little clarity in legislation and guidelines

3	<b>Monitoring of the system as a whole</b>	- Integration of services and systems	- Insufficient monitoring of services
4	<b>Occupational right and justice values in policies</b>	- Being mobile: a key to meaningful occupation	- Limited fit with occupational right and justice values

### 7.2.1 Key area 1 – Users’ involvement in policy development

It was clear from phase one of this study that users want to be autonomous and have control of their own lives. Findings from both study phases indicate that users are not involved in policy making as they should be. Furthermore, the policy review clearly identified lack of users’ involvement, and it was sometimes unclear if users were involved at all. For example, users were not included in the formal accessibility inspection and they were not involved when authorities evaluated if their plan of action goals were met. Even when the users were involved, such as when asked questions about the transportation service, they were asked leading questions, or the results interpreted in a favourable way for authorities. These findings are in line with a recent Icelandic study, which shows that users are not involved much in policy making and even though they are brought to the table, their voices are not incorporated into the final product (Löve, Traustadóttir & Rice, 2018).

These above-mentioned findings also demonstrate that policy making within the disability field in Iceland is not according to the CRPD. Involvement of users is given high priority in the CRPD. In the preamble of the CRPD, the importance of disabled people having the opportunities to influence the development of policies and their implementation is stressed. Additionally, it highlights the importance that disabled people should have autonomy, make their own choices, and “have the opportunity to be actively involved in decision-making processes about policies and programmes, including those directly concerning them” (p.2). Furthermore, one of the general obligations of the CRPD states that authorities “shall closely consult with and actively involve” (United Nations, 2006, p.6) disabled people when developing and implementing legislation and policies concerning them.

Disabled people are the experts in their own situation and need to have opportunities to be actively involved, incorporating their lived experiences, in the policy making process (Löve, Traustadóttir, Quinn & Rice, 2017). Lid (2014) highlights the importance of involving users as they have the “situated, embodied knowledge” (p.4) needed for design and planning that affects accessibility and universal design. The involvement of users is not only important to get their expert perspectives into the policy making, but also may reduce the power imbalance which often exists between users and officials (French & Swain, 2012). Additionally,

*“it is a challenge of professionals and managers in health and social care to ensure, not only that the involvement of disabled people is possible, but that it is extensive, meaningful and translated into practice with positive outcomes for disabled people’s lives” (French & Swain, 2012, p. 141)*

Therefore, Icelandic authorities need to find solutions to genuinely involve users in the policy process, ensuring it is done in a significant way, where the voices of disabled people are not excluded from the final documents.

### 7.2.2 Key area 2 - Clarity and consistency of policy texts

Currently, information in policy documents regarding transportation and accessibility in Iceland is contradictory which makes it confusing to know which information is valid. Additionally, due to lack of clarity, the current policy documents allow for various interpretations, which creates the risk that the implementations of those documents will not be consistent with the intent of that document, and not be according to the CRPD. Thus, national authorities, who are responsible for policy making in the field (Act no. 59/1992; Act no. 38/2018) need to prepare policy documents, such as regulations and guidelines for local authorities, with greater clarity to minimize the chance of implementation of insufficient services. Some recommendations for each service area are provided in chapter six but following is a discussion on why it is important to clarify the existing policy documents.

The need for policy texts to be clear, transparent and consistent relates to the principle of legal certainty, one of the basic principles of law. Legal certainty refers to “the requirement for the law to be clear and precise so that the subjects of law may have a clear knowledge of their rights and duties and use them accordingly” (Samuilytė-Mamontovė, 2014, p. 58). Thus, not only is clarity of policy texts needed to know what the rights of people are, but also so local authorities and service providers can know what their obligations are, and what is expected from them.

Clarifying policy texts will have implications for both service users and service providers. Having accessible information has been identified as helping disabled people to make important choices regarding services they use (Baxter and Glendinning, 2011). Thus, it is important for them to have access to information, and for this information to be transparent on what their rights are. The implication of clarifying the policies for the providers affects their capacity to take actions they are required to do to fulfil the obligations of the law, so the services will function as they should, and the rights of disabled people will be respected. Furthermore, clearly stated policies can facilitate accountability and can make it easier to hold authorities (both local and national) responsible for the enactment of those policies, as users and providers will understand what to expect, who has rights and responsibilities etc.



At this moment, it is especially important that authorities clarify regulations and guidelines that pertain to the newest changes in legislation. One example of a recent issue relates to these changes in legislation that should have come into effect on October 1<sup>st</sup>, 2018. Shortly before this change was supposed to take effect, the association of local authorities requested a postponement so that local authorities could delay providing some of the services in the new legislation. The reasons for this request were due to both a lack of guidelines on how to implement the new legislation, but also because of uncertainty regarding funding from national authorities (ruv.is, September 15<sup>th</sup>, 2018). This clearly affects users who have been waiting for certain services, and now might have to wait even longer.

### 7.2.3 Key area 3 – Monitoring of the system as a whole

One of the factors identified by service users and providers in phase one was the importance of integration of services and systems to better support community mobility. Mainly, the examples given were about the importance of communication and collaboration between service areas in order to back each other up. For example, in order for public transportation in Akureyri to be effective for people with mobility impairments, the snow removal team of the town needs to clear the snow off the sidewalks and from the bus shelters for users to be able to access the bus. These services need to work together. Thus, when developing and implementing any service for the

group, other services that intersect with that service (be affected or affect) will have to be considered as well.

Phase two identified limited monitoring of services for disabled people in Iceland. Monitoring could help with identifying loopholes within the system, so they can be fixed in order to support community mobility. If services and systems were monitored properly, it would be easier to see how integration could be improved and where it needs improvements. Thus, there is a need for centralised oversight of all rights of disabled people to form knowledge in the field and provide consistency in interpretation and implementation of policies and programs for disabled people, guarding their fundamental rights. A centralised oversight can then help to press social and legal change to address human rights issues.

The Icelandic authorities do not have to invent such a system from scratch but could look into approaches that have been used in other countries. One such approach is holistic monitoring approach developed by the Disability Rights Promotion International. This approach focuses on systemic monitoring where the experiences of disabled people are the “driving force of a viable disability rights monitoring process” (Dinca-Panaitescu, 2015, p. 83). Such an approach might be useful for Icelandic authorities to improve the policy implementation in the disability sector nationally and locally. According to the CRPD, disabled people “and their representative organizations, shall be involved and

participate fully in the monitoring process” (article 33 (3), p. 25). Additionally, it is essential that disabled people are involved in monitoring of the services provided by local authorities; “otherwise, there is a risk that human rights violations will be hidden at the local level” (Brennan, Rice, Traustadóttir & Anderberg, 2016, p. 344).

#### 7.2.4 Key area 4 - Occupational right and justice values in policies

Occupational right values refer to authorities’ recognition of the basic human right of individuals to have opportunities to do what is meaningful to them, or the principle that all people “have the right... to engage in meaningful occupations that contribute positively to their own well-being and the well-being of their communities” (Hammell, 2008, p. 62), whether it is moving around their communities, going to work, or taking part in social activities in the evenings with friends. However, in order to recognize these occupational rights, occupational justice values are needed to back it up, as it refers to authorities’ recognition that many people need support to have opportunities to partake in meaningful occupations, and it is the responsibility of the society or the state to provide such resources in an equitable manner (Wilcock, 2006). Thus, incorporation of occupational right and justice values in policy texts will both acknowledge the right of people to engage in various occupations, but also recognize the responsibility of authorities to support those occupations.

There are four findings from my research that indicate that occupational right and justice values should be incorporated into policy making. First, users from phase one clearly stated that they could not take part in some occupations they want to because of community mobility issues. Second, service providers gave multiple examples of users who did not have the opportunities to participate in the same occupations as their peers. Third, it was unclear from the policies analysed in phase two, which occupations are supported, for example, by the accessible transit service. And fourth, the policies did not align with the occupational rights values that exist within the CRPD, such as regarding being able to choose when and where to go somewhere.

The policy documents that were analysed do mention certain occupations (such as work and study) that the services aim to support, but there are certain occupational areas that are not covered, or insufficiently defined (such as leisure activities). Those silences regarding certain occupational areas may limit the opportunities people have to move between places, when that movement relates to those specific occupations. For example, the policies regarding transportation services do not address the needs of people to access social and cultural activities in the evenings. Consequently, as identified by the focus group participants, people with mobility impairments have difficulties accessing those occupations due to limited services in the evening.

If people are deprived of the opportunity to move around in the community, it violates their occupational rights in various ways, by limiting their chance to participate in society. Incorporating occupational right and justice values into Icelandic transportation and accessibility policies would enhance users' opportunities for diverse occupations that are meaningful to them, as well as support their community mobility to the different locations where those occupations take place. Thus, occupational right and justice values could enhance existing policies and strengthen them to meet both community mobility and other occupational needs of people with mobility impairments. Additionally, incorporation of occupational right and justice values would better align those policies with the CRPD which places importance on both community mobility and people's autonomy to make decisions and choices (such as regarding occupations), and for full inclusion in society (United Nations, 2006).

As an occupational scientist, I talk about occupational right and justice values. However, other terminology may be used outside of the occupational science field in order to facilitate discussion regarding what needs to change in policy. Instead of referring to occupational rights in such discussion, it would be clearer to discuss people's right to have opportunities to do what is meaningful to them. Instead of using the term occupational justice, it would be useful to talk about what resources people actually have to support what they choose to do. A model that could fit well to facilitate such a discussion is the capability approach as presented by Nussbaum (2011) (cf. Sen, 1999) as

it is consistent with both occupational rights and justice. Hammell (2017) suggested that the capabilities approach may be helpful to address occupational right issues by asking questions such as “what are people actually able to do and to be? What real opportunities are available to them? (Nussbaum, 2011, p. x). However, the capabilities approach can also address the occupational justice issues as it talks about the political, social, and economic conditions “in which functioning can actually be chosen” (p. 22). This approach puts emphasis on human dignity, diversity of people, autonomy and people’s freedom to choose on their terms. It takes into account that people are diverse and have different needs and thus some people, such as disabled people, may need more support and resources to have equal opportunities as other people. Thus, when thinking of the findings from the focus group discussions, the service users will need more transportation resources in the evenings and on weekends to allow them the freedom to choose the occupations in which they want to engage and be able to do so equally to others. Nussbaum (2011) states that the capability approach “reminds policy-makers that the goal is always to present people with choices... rather than to dragoon them into a specific mode of functioning. This emphasis on choice certainly shapes the strategies of implementation that policy-makers should consider” (p.97).

## 7.3 Implications

From the beginning of this PhD journey, I wanted my research to be pragmatic. I wanted to be able to answer the research questions in order to improve the policy making processes affecting community mobility for people with mobility impairments. I started my research by talking to service users and service providers, which helped me identify the policy areas of utmost importance for the community mobility of people with mobility impairments. The policy areas identified encompassed transportation services and accessibility, which is also supported by the findings from the scoping review presented in chapter two (Jónasdóttir & Polgar, 2018). I firmly believe that by involving users in policy development, having policy texts clear and consistent, monitoring the system as a whole, and incorporating occupational right and justice values into policies, the community mobility of people with mobility impairments in Akureyri may be improved.

Even though this dissertation has focused on the rights of each individual to engage in meaningful occupation, its main focus is on the system level factors that create injustices but have the power to ensure justice. The constraints in opportunities for community mobility can be linked to lack of clarity in policy text, insufficient involvement of service users, and thus lack of incorporations of their voices in policy text, as well as insufficient monitoring and limited focus in the policy text on supporting different occupations.

My intention is to share the knowledge I have gained from this journey to stakeholders in Iceland that may affect the way policy making is currently done in Iceland. I do realise that my research is not going to shift the policy context instantly. However, the findings can raise awareness within the policy sector, gradually shifting the mindset of those involved towards the importance of users' involvement, their opportunities to engage in meaningful occupations, as well as clarity and monitoring of policies and services to support disabled people to move around. Below are the implications that can be drawn from this dissertation for the occupational science field, service users, policy makers and service providers.

### 7.3.1 Implications for occupational science

I want to highlight how this dissertation can inform occupational science. First, participants talked about community mobility as an occupation, such as when they move around in the community on a beautiful day for their own enjoyment. But more so they talked about the importance of being able to move between places to engage in their preferred occupations that take place somewhere outside their own homes, such as going to the movies, visiting people, work, study etc. The American Occupational Therapy Association (2014) identified community mobility as an occupation; it has been identified further as essential for participation in society (Di Stefano et al, 2012). Still, little discussion can be found on the importance of this specific occupation for engagement in



other occupations. This study especially highlights the link between system level factors, community mobility and other occupations.

Second, scholars within occupational science have criticized studies within the field for their lack of focus on the higher-level contextual factors shaping occupation and for being too focused on the individuals (e.g. Farias, Rudman & Magalhães 2016; Gerlach, Teachman, Laliberte-Rudman, Aldrich & Huot, 2017; Gupta, 2016). The work presented in this dissertation further supports this claim and shows that those system level factors play an essential role in shaping community mobility for people with mobility impairments. Thus, these factors have to be considered to support the occupation of community mobility, instead of focusing mainly on the individual's situation and immediate context. The findings also show that when system level factors shape one form of occupation, they can consequently affect other forms of occupation. Not only do those factors affect community mobility, but also multiple other occupations that rely on people being able to freely move around in their communities.

Third, the concept of occupational justice has been discussed and developed since the 1990s. Even though it is a promising concept to inform social change, it has also been criticized for lack of clarity (Hammell, 2008; Durocher et al., 2014). Hammell (2008, 2017) pointed out the connection between human rights and occupation and proposed we use the term occupational rights. The work presented in this dissertation offers a

perspective on the connection between occupational justice and occupational rights. The findings of this study support the idea that those terms are interlinked and cannot be separated, especially when individuals need some extra support to engage in occupation. To explain further, I see occupational justice as the promotion of resources which leads to the outcome of fulfilling occupational rights. The findings of this study highlight how occupational injustices, leading to violation of occupational rights, originate in the policy context at local and national level. Even though occupational rights are the end goal, as suggested by Hammell (2017), occupational justice has to be addressed in order to reach that goal. Thinking of occupational justice and rights as interconnected may help us to focus more on identifying occupational injustices (lack of resources) leading to violation of occupational rights (people lack or are denied opportunities to do). Furthermore, the findings indicate that experiencing occupational injustices related to one occupation can lead to such injustices in other occupational areas as well. The participants in this study spoke to the difficulties people with mobility impairments have when the society does not provide the resources they need to support their community mobility, and the multiple ways such a lack of community mobility has on their other preferred meaningful occupations. This finding shows how lack of resources at the system level (occupational injustice) can lead to multiple violations of occupational rights.

Fourth, this work also adds to the growing body of literature that emphasises the connection between occupation and human rights (e.g. Hammell, 2008, 2017; Hocking

2017; Wilcock & Hocking, 2015). This work indicates that the CRPD can be a useful tool for occupational scientists to identify human rights issues that relate to occupation, such as occupational justice and right issues. The CRPD both identifies occupations as a human right, but also identifies certain resources or conditions that need to exist in society to support various occupations (United Nations, 2006). Occupations identified in the convention are for instance community mobility (article 20), education (article 24), work (article 27), leisure, sport and cultural life (article 30). Examples of required resources identified in the CRPD are provision of accessible environment (article 9), assistive technology and transportation (article 20), an inclusive education system (article 24) and promotion of employment opportunities (article 27). Furthermore, to promote equality, the CRPD specifies that “States Parties shall take all appropriate steps to ensure that reasonable accommodation is provided” (United Nations 2006, p.7). The CRPD also addresses issues at the system level such as training of professionals, awareness raising, involvement of disabled people at the policy level, and much more (United Nations, 2006) that relate to the terms occupational justice and rights. This is important for occupational scientists because in order to support occupation we need to identify those human right issues and ways to move things forward.

Finally, this work contributes to the occupational science field by providing new insights into the usability of case study methodology for the study of occupation. In chapter three, information was provided on what case study methodology is and how it may be used in

research related to the concept occupation. The chapter highlights important aspects that need to exist in a study for it to be considered a case study, and how those aspect could be implemented when studying occupation (Jónasdóttir, Hand, Misener & Polgar, 2018). However, we claimed in chapter three that even though case study methodology has been used to study occupation before, it has been used in a limited way. The methodology offers more creative and flexible ways that has the potential to capture the complexity of occupation as it occurs in context, especially if researchers broaden their scope of case studies, and shift their focus more towards the wider contextual factors instead of the individual situations.

### 7.3.2 Implications for service users

The findings of this study add to the literature on the importance of users being involved in the process of creating and developing policy on matters that affect them (Löve, Traustadóttir, Quinn & Rice, 2017; French & Swain, 2012). The findings also show that users are not involved as they want to be in making decisions regarding their services. To improve services that are designed for people to be able to move around, we need to hear and incorporate the voices of people who deal with the issues of community mobility every day. Even though others may benefit from such policy, they are the intended recipients of that policy and its implementation. I hope that this research, in addition to other studies in Iceland showing this lack of users' involvement (Löve, Traustadóttir,

Quinn & Rice, 2017), will help push authorities to change their way of informing policy both at national and local level.

There are multiple ways service users could, and should, be involved (United Nations, 2006). First, there should be direct involvement of people with mobility impairments in creating policies regarding accessibility and transportation at the national level and local level. For example, they should take part in creating policies directly at the ministry level, but also within the municipalities. Second, it would be beneficial to have direct communication between service users and service providers when developing services at the local level, where service users should have the opportunities to share their thoughts about the effectiveness of the service, and how the service could be improved to serve them better. Third, all service users should have the opportunity to voice their concerns and make decisions regarding the multiple services they are receiving as individuals. And lastly, service users should be actively involved in monitoring the services that are intended for them. It would be beneficial to have users involved in monitoring for multiple reasons, for example they will be able to identify if different services work well together. The outcome of the policies and their implementations can only be assessed by the intended recipients, in this case the people with mobility impairments. If the intent of a policy is to improve the lives of disabled people, the only people who can actually say if that impact has been reached is disabled people.

Due to lack of clarity and consistency in policy texts, it can be hard for service users to know what services are available to them and in what form. One example from the findings is regarding lack of information on accessible public buses, creating uncertainty among service users if they can use the public transportation or not. Another example is regarding lack of clarity on when the coupons for taxi services are valid, if it is anytime, or if it is only during times the accessible transit service is operating. These uncertainties degrade the usability of these services for users, as they don't know if and when they can use them. These barriers could be easily removed by reviewing all service information that is available to the public and make that information more accessible for service users. Such work could further be done with the involvement of service users. Having the policy texts and information about services clear, consistent and accessible for service users, could help service users to make informed decisions about the service options available (Baxter and Glendinning, 2011).

Additionally, this works highlights the importance of multiple different occupations for people with mobility impairments and how the system needs to support them in order to be able to access those occupations. As the system is today, service users cannot access all the occupations that are meaningful to them, such as spontaneous occupation or social occupations on weekends and evenings. The findings of this study can raise awareness of the importance of incorporating into policy texts more opportunities for service users to partake in society on an equal basis to others. Indeed, the CRPD highlights the

significance of “full and effective participation in society on an equal basis with others” (United Nations, 2006, p. 4) and thus, community mobility and other occupations that rely on community mobility should gain more attention within the disability policy field to support the human rights of disabled people.

### 7.3.3 Implications for policy makers

By signing the CRPD, and setting new legislation aligning with the CRPD, the Icelandic government is setting clear lines regarding their policy in the disability field, and consequently regarding the level of services they intend to implement for disabled people. Despite policy makers' intentions and efforts to develop Icelandic policy texts to fulfill the requirements of the CRPD, the findings of this study show that goal has not been reached yet. A long time has passed since authorities signed the CRPD and the fact that they still have not implemented services according to convention, indicates that there are some struggles at the system level that need to be solved. The work presented in this dissertation identifies policy issues and suggest certain steps that national and local authorities can take in order to improve policies around transportation services and accessibility.

For authorities to improve their policies, their policy making process will have to be revised, especially regarding involvement of disabled people. Every effort should be made to include disabled people in in the policy making team, and in every step of the

policy process, including identification of the problem the policy needs to address, policy formulation, implementation and evaluation, as well as all revisions made along the way.

National authorities will need to set clear policies and guidelines regarding both transportation services and accessibility to improve community mobility for people with mobility impairments. Policy makers also need to make sure that there is no contradicting information in different policy documents. Examples of such contradictions that policy makers should avoid can be seen in the findings of this study. The first was found in different documents that pertain to the accessible transit service in Akureyri regarding what type of activities the service supports (Town of Akureyri, 2010; Act no. 37/2018). Additionally, checklists regarding accessibility in new buildings give contradicting information on the significance of accessibility, as the same accessibility issues have high priority in one checklist, but no priority in the next, such as wheelchair accessibility in theatres (Iceland construction authority, 2018a).

The policy texts created at the national level will need to support that people will receive means of transportation that are accessible, flexible and affordable, whether it is in the form of taxi, the accessible transit service vehicles or something else. As stated before, according to the CRPD and the newest legislation changes in Iceland, disabled people should be able to choose where they want to go, at what time and by means that are



affordable (United Nations, 2006; Act no. 37/2018), and thus authorities need to establish policies and services that meet those requirements.

Efforts to raise awareness regarding accessibility and the importance of accessibility to the physical environment should also be incorporated into policy. It should be kept in mind that such an awareness needs to be raised for the general public, and for all levels of the service system. By levels of the service system, I mean policy makers at the national level, policy makers at the local level, as well as service providers. Interestingly, in order for this awareness efforts to be implemented into policy, awareness within the highest level of the system has to be raised first.

In order to enhance the occupational justice and right values in policies, I suggest that policy making teams ask questions similar to the ones presented in the capabilities approach, such as what opportunities our current policies give to people to actually be able to do (Nussbaum, 2011). The findings of such questioning can then be compared to the CRPD to see where similarities and discrepancies are, and based on those findings, changes to the current policy need to be made.

For the evaluation stages, the intended outcomes of the policies will have to be considered, as well as how those outcomes can be measured. According to the act on services for disabled people with long-term need for support (Act no. 38/2018) it is the

responsibility of the Minister of Social Affairs and Children to monitor the implementation of services for disabled people. Recently, a new agency was established by national authorities which aims to monitor services for disabled people (Government offices of Iceland, n.d.). However, little information can be found about the role and responsibilities of this agency, and in fact, no information can be found on any independent mechanism to monitor those implementations, as required by the CRPD (United Nations, 2006 article 33 (2)). Thus, it is highly important that such a mechanism is established, which should have the responsibility of monitoring policies at both national and local levels, as well as the implementation of those policies.

#### 7.3.4 Implications for service providers

Even though national authorities make the policies, local authorities are accountable for providing the services according to the prioritisation of national authorities. In order to provide services that are according to the CRPD and are acceptable by service users, there are aspects that are identified in this dissertation that are especially important. First the service users need to be consulted on what needs to be done to improve the services. Second, in that process, the service users should be asked about what is important for them, what activities they need those services to support, and how they would be best supported to access those activities. This could be done both at an individual level, such as when people apply for services, and at a community level by having public meetings

or group discussions where people with mobility impairments have the opportunity to voice their concerns and suggestions.

At the individual level, service providers will have to incorporate communication with each individual service user to be able to recognize and understand his unique needs for services, as people are different and have different needs. Also, as the findings from this study suggest, each person can have different needs for services between days and weeks, which requires the services and service providers to be flexible. Additionally, if we consider the fulfillment of occupational rights as the preferred outcome of a policy, it is clear that these outcomes will have to be defined by the individuals who are entitled to those rights. If occupational rights are “the rights of all people to engage in meaningful occupations that contribute positively to their own well-being and the well-being of their communities” (Hammell, 2008, p.62), each individual will have to identify what is meaningful occupation for him/her. This further emphasises the importance of listening to the voices of the service users in order to provide appropriate resources to support those individuals’ occupational rights. Thus, neither policy makers nor service providers can decide which occupations are meaningful to service users and should be supported by the system.

To improve the services, service providers should also ask users when evaluating if a service meets the need of the users. They are the ones that could tell if the services are

well designed and if they are implemented effectively. For example, if a service is supposed to support service users' transportation to their preferred locations at the time of their choice, is that goal reached? Why? Why not? Such questioning could partially serve as a monitoring of the service provision. Another key idea of the capabilities approach is that it is insufficient to simply offer a service if the person does not have the opportunity or capability to take advantage of it (Nussbaum, 2011). For example, it is insufficient to offer accessible transportation if it does not support the user's choice of when and where to go and what to do when they get there. Another example is that it is insufficient to provide accessible bus shelters or sidewalks if snow removal (or objects placed on the sidewalk) prevent persons with mobility impairments from using the shelters or sidewalks. The strength of the capabilities approach is that it requires service providers to think beyond the basic service to include other elements that affect user's ability to access and use the service. The approach challenges service providers to go beyond the basics to provide full opportunities to use and benefit from their service.

Additionally, awareness needs to be raised between service providers regarding issues that are brought to their attention and relates to the services they are providing. Such an awareness has the potential to improve the integration of different services. For example, the public transportation services need to let the snow removal services know of issues that arise from not removing snow at bus stops. Also, service providers who are in constant communication with service users and are aware of their multiple issues relating

to accessibility should contact the relevant department at the municipality to address the issues. For example, service users who often go with people with mobility impairments around town and see them dealing with accessibility hindrances, should inform authorities for the need to remove those hindrances.

If the national and local level do not reach an agreement, such as regarding funding for policy implementation, it can also create uncertainty for the people providing services. Because even though authorities have not reached perfect agreement on how to implement certain aspect of the new legislation, they bear responsibility towards disabled people as they are entitled to certain level of services that local authorities are responsible for providing. The national authorities create the policies that local authorities will need to take into account in decision making regarding their own policies. However, the general service provider will not have the power to make those decisions but works under the conditions that are created by people at higher levels (both nationally and locally). Thus, I believe it would be beneficial for service providers to establish some ways to identify the contradictions in policy documents and communicate them to higher levels that have the power to rectify them.

## 7.4 Limitations

It has to be acknowledged, that doing an extensive case study, like the one presented in this dissertation, can feel like a never-ending story. The reason is that digging into the policy field like this can never grasp the totality of the case. When doing a case study, data should be collected from multiple sources because when we attempt to gain comprehensive understanding of the case, we need to study it from various viewpoints (Baxter & Jack, 2008; Berg & Lune, 2012; Jensen & Rodgers, 2001; Merriam, 1997). The amount of data and the multiple perspectives that could have been collected for the purpose of this study is extensive and hard to bound. Thus, even though this study has contributed to understanding of this particular case, a complete understanding of it will never be achieved. Even if resources were available to cover every perspective and collect all data at a given point in time, the policy field is dynamic and constantly evolving which means that there are always new perspectives and new data generating. That also means that although the search for documents was extensive, and some texts or ideas that national or local authorities are currently working on might not have been found or even publicly available. Still, this research gives us important information and understanding on how the case of Icelandic transportation and accessibility services, systems and policies restrict or support community mobility for people with mobility impairments in Akureyri.

The first phase of this study is based on information from only 14 individuals, 8 service users and 6 service providers. However, based on publicly available numbers, it is estimated that there is about 70 individuals with mobility impairments in Akureyri (Statistics Iceland, 2014), and thus, these 8 service users represent over 11% of that population. Additionally, the policy areas highlighted by the participants are the same as were most commonly reported on in the articles reviewed for the scoping review presented in chapter two, that is regarding accessibility and transportation services (Jónasdóttir & Polgar, 2018). Even though the results may not be generalizable, which was never the intention of this study, the findings give us valuable information on what users and providers experience as barriers and what they consider as important to incorporate into policy making in Iceland. Furthermore, the policy analysis gives us further details regarding these specific service areas identified by service users and providers in phase one.

Even though the case was defined in the beginning of the study process as the implementation of any Icelandic services, systems, and policies that restrict or support community mobility for people with mobility impairments in Akureyri, it later narrowed down into specific services, systems and policy areas that shape community mobility for this group. However, the second phase of this study, which analysed policy documents, only covers analysis of the written texts, not exploration on how local and national authorities are actually implementing the written policies, and if the implementation is

according to the policies. This means that the implementation part of those policies, or how the services operate in reality, was not addressed in the second phase. However, the first phase gave us information on the implementation from the perspective of service users, or how those services translate into their everyday life. To continue with this case study, it would be beneficial to do a follow up on the second phase, to explore further the actual implementation, from the perspective of authorities, service providers, as well as service users.

Preferably, a research like this one should be done in partnership with people with mobility impairments. Unfortunately, this was not done due to the fact that I was located in Canada, and as a result of time constraints when conducting research as a graduate student. Service users were thus not involved in designing of the research, such as deciding the scope of it and the research questions. Additionally, even though participants from the focus groups were given opportunity to give feedback on the findings, no service users did that. I believe it would be beneficial in later stages of this research to collaborate with the experts – the people with mobility impairments throughout the whole research process.

Additionally, doing research in two languages is time consuming and complex. Because data were collected in Icelandic and then translated into English, there is a possibility that some of the meaning was lost. Still, I tried to counter this limitation by having an



Icelandic member of the advisory committee, who is fluent in both languages, perform an audit to detect if there were any discrepancies between the Icelandic and the English versions of the data.

## 7.5 Future research directions

Even though this PhD journey gave some answers to my questions, this work raised more questions that still need to be answered. For every question answered, further questions were raised, which highlights the complexity of this research topic. Based on these questions, here are some suggestions for future research.

An examination of the actual policy implementation, both from service users and service providers perspectives, might be valuable. In order to assess how successful, the implementation of these policies is, it has to be considered how they translate into everyday life situations of disabled people. For example, further exploration of how the accessible transit services or accessibility shapes community mobility, and consequently other occupational possibilities of disabled people. Also, more from a service providers perspective, exploration of what shapes the way policies around accessible transit services are implemented would provide an understanding of the challenges they face to provide fully accessible services. Such a study could also look at how the financial aspects of these service fields affect its actual implementation.

Additionally, as the user controlled personal assistant services were not analysed for this study, this service area should be examined when some stability and clarity regarding its implementation has been reached within the Icelandic policy context.

Since both study phases of this case study highlighted the importance of service users being involved in policy making, I think it would be worthwhile to examine what the barriers for such involvement in the policy process are. Furthermore, such a study could also look at potential strategies that would support users' involvement in development and enactment of policies.

And lastly, both from speaking to stakeholders and analysing policy texts, it was clear that leisure activities have little significance in policy texts, which is another topic that may be of interest, especially for scholars within occupational science. Why is leisure seen as less important than other occupations within policy texts? I found this especially interesting since this suppression of leisure seems to exist in other policy areas in Iceland, such as regarding assistive technology provision, where people cannot get assistive technology specifically to assist them with leisure activities (Regulation no. 1155/2013).

## 7.6 Conclusion

The objective of this dissertation was to enhance our understanding of services, systems and policies affecting community mobility of people with mobility impairments in the

town of Akureyri, Iceland. The findings of this study reveal that people with mobility impairments in this location encounter various hindrances at the system level to their community mobility that relate to transportation services and accessibility. The findings also indicate certain steps that authorities in Iceland could implement in their policy processes to better support community mobility of people with mobility impairments, such as involving users in the policy processes, clarify their policy texts, establish a proper monitoring mechanism, and to incorporate occupational justice and rights values into their policy texts and implementations.

Furthermore, the findings reveal important information regarding community mobility as an occupation and as a means to occupation. Community mobility for people with mobility impairments is very important because if they cannot move around in their communities, they cannot fully participate in society. Multiple examples were identified of how lack of community mobility opportunities, due to insufficient support at the system level, limit their engagement in other occupations. Ergo, people with mobility impairments in Akureyri are subject to occupational injustices and violation of occupational rights, which only can be rectified at the system level.

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## Appendices

### Appendix A: Approval from Western University research ethics board



**Office of Research Ethics**  
Support Services Building, Western University  
London, Ontario, Canada, N6A 3K7

#### RECOMMENDATIONS FORM HEALTH SCIENCE RESEARCH ETHICS BOARD

**Delegated Review – Level 2**

HSREB Chair: Dr. Joseph Gilbert

**Ethics Officer: Grace Kelly**

*Please note your study may not commence until you receive final notification of approval from the Office of Research Ethics (ORE).*

#### PROTOCOL DETAILS

Review Date	July 31, 2014
Research Ethics Board ID*	105537
Study Title	Governance factors support for community mobility: People with mobility limitations in Akureyri
Principal Investigator	<b>J. Polgar</b>

\*This number must be quoted on all modifications, revisions and correspondence.

#### PROTOCOL STATUS

The proposed study submission has been reviewed and the following decision has been reached:

#### **APPROVED - NO CHANGES REQUIRED**

Please note that the submission has now been reviewed by an ORE reviewer(s) and there are no recommendations at this time. Please note that this letter is being sent as acknowledgment that no changes are required. You **MUST NOT** begin any part of your research until you have received final notification of approval from our office.



Western University Health Science Research Ethics Board  
HSREB Delegated Initial Approval Notice

Principal Investigator: Dr. Jan Polgar  
Department & Institution: Health Sciences/Faculty of Health Sciences, Western University

HSREB File Number: 105537

Study Title: Governance factors support for community mobility: People with mobility limitations in Akureyri  
Sponsor:

HSREB Initial Approval Date: August 19, 2014  
HSREB Expiry Date: October 31, 2015

Documents Approved and/or Received for Information:

Document Name	Comments	Version Date
Letter of Information & Consent	Informed consent form, english version	2014/07/07
Recruitment Items	Email script, focus group B, english version	2014/07/08
Letter of Information	Information letter for focus group B	2014/07/08
Letter of Information	Information letter for focus group A, english version	2014/07/08
Instruments	Additional information, questionnaire for focus group B, english version	2014/07/08
Instruments	Additional information, questionnaire for focus group A, english version	2014/07/08
Other	Introduction in the beginning of focus group B, english version	2014/07/08
Other	Introduction in the beginning of focus group A, english version	2014/07/08
Instruments	Question guide for focus group A - english version	2014/07/08
Instruments	Question guide for focus group B - english version	2014/07/08
Recruitment Items	Collaboration agreement to find potential participants for focus group B. English version	2014/07/01
Recruitment Items	Collaboration agreement to find potential participants for focus group A. English version	2014/07/01
Letter of Information	Information letter for focus group B. Icelandic version	2014/06/01
Letter of Information & Consent	Informed consent form for both focus groups. Icelandic version	2014/06/01
Recruitment Items	Collaboration agreement to find potential participants for focus group B. Icelandic version	2014/06/27
Recruitment Items	Collaboration agreement to find potential participants for focus group A. Icelandic version	2014/05/26
Letter of Information	Information letter for focus group A. Icelandic version	2014/06/01
Instruments	Questionnaire for gathering additional information. Focus group A. Icelandic version	2014/06/01
Instruments	Questionnaire for gathering additional information. Focus group B. Icelandic version	2014/06/01
Instruments	Introduction in the beginning of focus group interview. Group A. Icelandic version	2014/06/01
Instruments	Introduction in the beginning of focus group. Group B. Icelandic version	2014/06/01
Instruments	Question guide for focus group A. Icelandic version	2014/06/01
Instruments	Question guide for focus group B. Icelandic version	2014/06/01
Western University Protocol		2014/07/11

The Western University Health Science Research Ethics Board (HSREB) has reviewed and approved the above named study, as of the HSREB Initial Approval Date noted above.

HSREB approval for this study remains valid until the HSREB Expiry Date noted above, conditional to timely submission and acceptance of HSREB Continuing Ethics Review. If an Updated Approval Notice is required prior to the HSREB Expiry Date, the Principal Investigator is responsible for completing and submitting an HSREB Updated Approval Form in a timely fashion.

The Western University HSREB operates in compliance with the Tri-Council Policy Statement Ethical Conduct for Research Involving Humans (TCPS2), the International Conference on Harmonization of Technical Requirements for Registrations of Pharmaceuticals for Human Use Guideline for Good Clinical Practice/Practices (ICH E6 R1), the Ontario Personal Health Information Protection Act (PHIPA, 2004), Part 4 of the Natural Health Product Regulations, Health Canada Medical Device Regulations and Part C, Division 5, of the Food and Drug Regulations of Health Canada.

Members of the HSREB who are named as Investigators in research studies do not participate in discussions related to, nor vote on such studies when they are presented to the REB.

The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.



Ethics Officer to Contact for Further Information

 Erika Basile ebasile@uwo.ca	 Grace Kelly grace.kelly@uwo.ca	 Mina Mekhal mmekhal@uwo.ca	 Vikki Tran vikki.tran@uwo.ca
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**Appendix B: Continuing ethics approval notice**



**Western  
Research**

Research Ethics

**Western University Health Science Research Ethics Board  
HSREB Annual Continuing Ethics Approval Notice**

**Date:** July 29, 2015  
**Principal Investigator:** Dr. Jan Polgar  
**Department & Institution:** Health Sciences\Faculty of Health Sciences, Western University

**Review Type:** Expedited  
**HSREB File Number:** 105537  
**Study Title:** Governance factors support for community mobility: People with mobility limitations in Akureyri  
**Sponsor:**


**HSREB Renewal Due Date & HSREB Expiry Date:**  
 Renewal Due -2016/08/31  
 Expiry Date -2016/10/15

The Western University Health Science Research Ethics Board (HSREB) has reviewed the Continuing Ethics Review (CER) Form and is re-issuing approval for the above noted study.

The Western University HSREB operates in compliance with the Tri-Council Policy Statement Ethical Conduct for Research Involving Humans (TCPS2), the International Conference on Harmonization of Technical Requirements for Registration of Pharmaceuticals for Human Use Guideline for Good Clinical Practice (ICH E6 R1), the Ontario Freedom of Information and Protection of Privacy Act (FIPPA, 1990), the Ontario Personal Health Information Protection Act (PHIPA, 2004), Part 4 of the Natural Health Product Regulations, Health Canada Medical Device Regulations and Part C, Division 5, of the Food and Drug Regulations of Health Canada.

Members of the HSREB who are named as Investigators in research studies do not participate in discussions related to, nor vote on such studies when they are presented to the REB.

The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

 Chair

Ethics Officer to Contact for Further Information

<input type="checkbox"/> Erika Basile ebasile@uwo.ca	<input type="checkbox"/> Grace Kelly grace.kelly@uwo.ca	<input checked="" type="checkbox"/> Mina Mekhail mmekhail@uwo.ca	<input type="checkbox"/> Vikki Tran vikki.tran@uwo.ca
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## Appendix C: Approval from the National Bioethics Committee in Iceland



VÍSINDASIÐANEFND

Hafnarhúsið, Tryggvagata 17  
101 Reykjavík,

Sími: 551 7100, Bréfsími: 551 1444

netfang: vsn@vsn.is www.vsn.is

Snæfríður Þóra Egilson, Principal Investigator  
Sæviðarsundi 39  
104 Reykjavík  
Iceland

Reykjavík 13. júní 2014  
Tilv.: VSNb2014060006/03.07

Efni: Regarding: 14-089-CM Study name: Governance factors support for community mobility:  
People with mobility limitations in Akureyri  
Icelandic: Stuðningur af stjórnáslulegum þáttum til að fara á milli staða í samfélaginu: Fólk með hreyfihamlanir á Akureyri.

To whom it may concern

This is to confirm that your study above was reviewed by the National Bioethics Committee, Iceland at its meeting on June 10th 2014.

Besides you as the Principal Investigator, the following scientists are collaborating in the study: Sigrún Kristín Jónasdóttir, Graduate Student, Health and Rehabilitation Sciences, University of Western Ontario and Jan Polgar, Associate Professor, School of Occupational Therapy, Western University, London, Ontario, Canada.

Enclosed with your application was a copy of the research protocol.

At its meeting, June 10th 2014, the National Bioethics Committee, Iceland granted your research proposal its full approval.

Sincerely,  
on behalf of the National Bioethics Committee

## Appendix D: Information letter for service users - Icelandic



### ***Stuðningur af stjórnáslulegum þáttum til að fara á milli staða í samfélaginu: Fólki með hreyfihamlanir á Akureyri***

Ábyrgðarmaður: Dr. Snæfríður Þóra Egilson, prófessor við félagsvísindasvið Háskóla Íslands,  
S. [REDACTED]

Tilfni þessa bréfs er að bjóða þér að taka þátt í rýnihópaumræðu sem er hluti af rannsókninni: *Stuðningur af stjórnáslulegum þáttum til að fara á milli staða í samfélaginu: Fólki með hreyfihamlanir á Akureyri*. Rannsóknin er liður í doktorsnámi Sigrúnar Kristínar Jónasdóttur í heilbrigðis- og endurhæfingarvísindum við Western Háskóla í London, Ontario, Kanada. Markmið rannsóknarinnar er að varpa ljósi á hvernig stjórnáslulegir þættir geta auðveldað fólki með hreyfihamlanir að komast á milli staða í samfélaginu. Þessir þættir verða skoðaðir út frá sjónarhorni fólks með hreyfihamlanir sem og fólks sem hefur reynslu af því að skipuleggja og/eða veita þjónustu til fatlaðs fólks.

Sá hluti rannsóknarinnar sem þér býðst að taka þátt í felur í sér rýnihópaumræður með fólki með hreyfihamlanir. Þér er boðin þátttaka vegna tengsla við Endurhæfingarstöð Sjálfsbjargar á Akureyri. Við erum að leita eftir einstaklingum sem hafa notað hjólastól, rafmagnshjólastól eða göngugrund daglega í að minnsta kosti 18 mánuði og sem hafa reynslu af því að fara á milli staða í samfélaginu (að minnsta kosti tvisvar í viku). Ennfremur þurfa þátttakendur að vera 18 ára eða eldri, búa í sjálfstæðri búsetu og vera færir um að taka virkan þátt í umræðum. Ef þú uppfyllir öll ofangreind skilyrði getur þú tekið þátt í rannsókninni.

Í rýnihópnum verður rætt um það hvernig þjónusta, aðstoð, stefna stjórnvalda og aðrir stjórnáslulegir þættir geti auðveldað fólki með hreyfihamlanir að komast á milli staða í samfélaginu. Þú verður einnig beðin/n um að svara stuttum spurningalista sem veitir

Bls 1/3

Dagsetning

Upphafsstafir þátttakanda

rannsakendum viðbótarupplýsingar til að fá betri innsýn í samsetningu hópsins og reynslu hans. Í spurningalistanum verður spurt um notkun þína á hjólastól/göngugrind og þætti tengda því að fara á milli staða í samfélaginu. Áætlað er að hópurinn samanstandi af 5-7 einstaklingum og að umræðan taki 1-2 klukkustundir. Umræðan mun fara fram á Akureyri (nánari staðsetning ákveðin síðar).

Umræðan verður hljóðrituð og síðan afrituð. Nafnleyndar verður gætt í öllum skrifum sem tengjast rannsókninni. Undirritaðar hafa einar aðgang að þeim upplýsingum sem þátttakendur veita. Farið verður með allar upplýsingar sem trúnaðarmál og þess vandlega gætt að ekki verði hægt að rekja þær. Ekki er hægt að tryggja nafnleynd innan hópsins þar sem miklar líkur eru á að þátttakendur þekki til hvers annars. Athugið að þátttakendum ber að gæta fyllsta trúnaðar varðandi upplýsingar sem tengjast öðrum meðlimum hópsins. Við úrvinnu gagna verður hluti þeirra þýddur yfir á ensku.

Þátttakendum verður einnig boðið að veita samþykki fyrir að haft verði samband við þá aftur símleiðis eða gegnum tölvupóst meðan á gagnagreiningu stendur til að koma með athugasemdir við grunniðurstöður.

**Það er undir þér komið hvort þú samþykkir þátttöku. Einnig er þér frjálst að hætta þátttöku á hvaða stigi sem er án útskýringa eða nokkurra afleiðinga.**

Þú munt ekki hagnast beint af rannsókninni sjálf/ur, en þátttaka þín er framlag sem getur nýst við skipulag og framkvæmd þjónstu við fatlað fólk. Niðurstöður rannsóknarinnar geta einnig nýst við frekari rannsóknir á áhrifum stjórnáslulegra þátta á samfélagsþátttöku fatlaðs fólks. Engir þekktir áhættuþættir fylgja því að taka þátt í þessari rannsókn. Rannsóknin hefur fengið leyfi Vísindasiðanefndar og verið tilkynnt til Persónuverndar.

**Fyllsta trúnaðar verður gætt varðandi allar upplýsingar sem aflað verður í rannsókninni.**

Farið verður með persónuupplýsingar og skráningu þeirra í samræmi við lög nr. 77/2000 um persónuvernd og meðferð persónuupplýsinga. Allar upplýsingar sem gefnar verða í viðtölunum verða geymdar í rafrænum skráum sem varðar eru með lykilorði. Allt efni verður svo vistað undir dulkóðun á fartölvu áður en það verður flutt frá Íslandi til Kanada. Engin



persónueinkenni verða geymd með gögnunum. Gögn á pappírformi verða ávallt geymd í læstum hirslum. Frumgögnum, ljósritum og tölvugögnum sem fela í sér persónueinkenni verður eytt að rannsókn lokinni og eigi síðar en haustið 2020.

Niðurstöður rannsóknarinnar verða kynntar við doktorsvörn rannsakanda við Western Háskóla í Kanada, ásamt því að stefnt er að því að gera grein fyrir helstu niðurstöðum á því stjórnáslustigi á Íslandi sem niðurstöðurnar tengjast. Ennfremur kunna niðurstöður að verða nýttar við greinaskrif í fagtímarit. Þátttakendur geta einnig fengið sendar til sín meginniðurstöður ef þeir óska þess.

Með virðingu og vinsemd,

\_\_\_\_\_  
Dr. Snæfríður Þóra Egilson, prófessor við  
Félagsvísindasvið Háskóla Íslands.

\_\_\_\_\_

\_\_\_\_\_  
Sigrún Kristín Jónasdóttir,  
doktorsnemi við Western  
Háskóla, London, Ontario,  
Kanada.

\_\_\_\_\_

\_\_\_\_\_  
Dr. Jan Polgar, prófessor við Western  
Háskóla, London, Ontario, Kanada.

\_\_\_\_\_

*Ef þú hefur spurningar um rétt þinn sem þátttakandi í vísindarannsókn eða vilt hætta þátttöku í rannsókninni getur þú snúið þér til Vísindasiðanefndar, Hafnarhúsinu, Tryggvagötu 17, 101 Reykjavík. Sími: 551-7100, fax: 551-1444, tölvupóstfang: vsn@vsni.is.*

*Þetta eintak er fyrir þig til að geyma*

## Appendix E: Information letter for service users – English



### ***Governance factors support for community mobility: People with mobility limitations in Akureyri***

Principal investigator: Dr. Snæfríður Þóra Egilson, professor at faculty of Social Sciences, University of Iceland, phone: [REDACTED]

The purpose of this letter is to invite you to participate in a focus group discussion which is part of the study: *Governance factors support for community mobility: People with mobility limitations in Akureyri*. The study is a project within Sigrún Kristín Jónasdóttir's doctoral program in Health and Rehabilitation Sciences at Western University, London, Ontario, Canada. The aim of the study is to shed light on how governance factors can support people with mobility limitations to go between places within the community. These factors will be examined from perspective of people with mobility limitations, as well as people that have experience of planning and/or providing services to disabled people.

The part of the study that you are invited to participate in includes focus group discussion with people with mobility limitations. You are invited to participate because of your connection to the Rehabilitation center of Sjálfsbjörg in Akureyri. We are looking for individuals who have used wheelchair, powered wheelchair or a walker on a daily basis for at least 18 months period, and have experience of going between places within the community (at least twice a week). Furthermore, participants must be 18 years or older, live independently and be able to actively participate in discussions. If you meet all the above requirements you can take part in the study.

Bls 1/3

Date

Participant initials

8 Oct. 14

The focus group will discuss how services, support, governmental policies and other governance factors can make it easier for people with mobility limitations to go between places in the community. You will also be asked to answer short questionnaire that gives the researchers additional information to get better insight into the composition of the group and its experience. Questions in the questionnaire will ask about your use of wheelchair/walker and factors that relate to moving between places in the community. Estimated number of participants in the group is 5-7 persons and the discussion will take 1-2 hours. The discussion will take place in Akureyri (exact location to be decided later)

The discussion will be audio recorded and transcribed. Only the research team will have access to information that participants give. Anonymity will be ensured in all writings related to the study. All information will be treated as confidential and care will be taken so they are untraceable. Anonymity within the group cannot be guaranteed because the likelihood of participants being familiar with each other. Please note that participants should maintain confidentiality regarding any information related to other members of the group. During data analysis, part of the data will be translated into English.

After the discussion, participants will be invited to give their consent for researchers to contact them again through telephone or email during the data analysis process to provide feedback on primary results.

**It is up to you whether you accept participation. Also you are free to withdraw from the study at any stage without explanation or any consequences.**

You will not benefit directly from the research, but your participation can be a useful contribution for planning and implementing services for disabled people. Results from the study can also be useful for further research on governance factors' impact on participation in the society for disabled people. There are no known risk factors in taking part in this study. The study has been approved by the National Bioethics Committee of Iceland and reported to the Data Protection Authority.

Bls 2/3

Date

Participant initials

8 Oct. 14

Complete confidentiality will be maintained regarding all information that will be obtained in the study. Personal information will be treated and registered in accordance with Act. 77/2000 on Personal Data Protection and Privacy. All data from the interviews will be in password-protected files stored on an encrypted laptop before it will be transferred from Iceland to Canada. No personal identifiers will be stored with the data. Electronic files will only be shared between members of the research team. Printed documents will be stored in locked cabinets at all times. Original documents, photocopies and computer data that include personal information will be destroyed after the study and no later than the fall of 2020.

Results from this study will be presented when the student, Sigrún Kristín Jónasdóttir, will defend her dissertation at Western University in Canada. Also the aim is to present the main results at relevant administrative level in Iceland. Furthermore, results may be used in articles in profession journals. Participants can also receive summary of findings if they wish.

With respect and kindness,

\_\_\_\_\_  
Dr. Snæfríður Þóra Egilson, professor in the  
Faculty of Social Science, University of  
Iceland

\_\_\_\_\_  
Sigrún Kristín Jónasdóttir, Doctoral  
student at Western University,  
London, Ontario, Canada.

\_\_\_\_\_  
Dr. Jan Polgar, professor at Western  
University, London, Ontario, Canada. email:

*If you have any questions about your rights as a research participant or if you want to withdraw from the study you may contact the office of the national ethics board, Tryggvagata 17, 101 Reykjavík. Telephone: 551-7100, fax: 551-1444, email: vsn@vsn.is*

Bls 3/3

*This letter is yours to keep for future reference.*

Date

Participant initials

8 Oct. 14

## Appendix F: Email script for recruitment of service providers – Icelandic

Komdu sæl/sæll (nafn viðkomandi)

Ég heiti Sigrún Kristín Jónasdóttir og er doktorsnemi í heilbrigðis- og endurhæfingarvísindum við Western Háskóla í London, Ontario, Kanada. Ég er að vinna að rannsókn sem fjallar um hvernig þjónusta, aðstoð, stefna stjórnvalda og aðrir stjórnsýslulegir þættir geti auðveldað fólki með hreyfihamlanir að komast um í samfélaginu.

Nú er ég að leita eftir þátttakendum fyrir rýnihópaviðtal með fólki sem hefur reynslu af því að skipuleggja og/eða veita þjónustu til fatlaðs fólks á Akureyri.

Þú ert einn af þeim einstaklingum sem ég tel að búi yfir þekkingu og reynslu sem tengjast málefninu. Ég yrði því þakklát ef þú myndir íhuga það hvort þú viljir taka þátt og ég hvet þig til að kynna þér nánari upplýsingar um rannsóknina sem fylgja hér í viðhengi.

Ef þú hefur áhuga á að taka þátt í rannsókninni máttu gjarnan svara þessum tölvupósti. Í framhaldinu myndi ég svo hafa við þig samband til að skipuleggja síma- eða skype fund til að ræða málin betur. Einnig ef þú hefur einhverjar spurningar varðandi rannsóknin þá hikaðu ekki við að spyrja.

Með virðingu og vinsemd

Sigrún

## Appendix G: Email script for recruitment of service providers – English

Hello ( person's name )

My name is Sigrún Kristín Jónasdóttir and I am a doctoral student in Health and Rehabilitation Sciences at Western University in London, Ontario, Canada. I am doing research on how services, support, governmental policies and other governance factors can make it easier for people with mobility limitations to go between places in the community

Now I am looking for participants for a focus group interview with people who have experience of planning and/or providing services to disabled people in Akureyri.

You are one of those people that I consider to have knowledge and experience in this field. I would therefore be grateful if you would consider the possibility of participating, and I encourage you to read further details of the study attached to this email.

If you are interested in taking part in the study, please respond to this email. Subsequently, I will then contact you and schedule a meeting over phone or skype to discuss better this project and your participation. Also if you have any questions about the study then do not hesitate to ask.

With respect and kindness

Sigrún

## Appendix H: Information letter for service providers – Icelandic



### ***Stuðningur af stjórnsýslulegum þáttum til að fara á milli staða í samfélaginu: Fólk með hreyfihamlanir á Akureyri***

Ábyrgðarmaður: Dr. Snæfríður Þóra Egilson, prófessor við félagsvísindasvið Háskóla Íslands,  
S: [REDACTED]

Tilfni þessa bréfs er að bjóða þér að taka þátt í rýnihópaumræðu sem er hluti af rannsókninni: *Stuðningur af stjórnsýslulegum þáttum til að fara á milli staða í samfélaginu: Fólk með hreyfihamlanir á Akureyri*. Rannsóknin er liður í doktorsnámi Sigrúnar Kristínar Jónasdóttur í heilbrigðis- og endurhæfingarvísindum við Western Háskóla í London, Ontario, Kanada. Markmið rannsóknarinnar er að varpa ljósi á hvernig stjórnsýslulegir þættir geti auðveldað fólki með hreyfihamlanir að komast á milli staða í samfélaginu. Þessir þættir verða skoðaðir út frá sjónarhorni fólks með hreyfihamlanir sem og fólks sem hefur reynslu af því að skipuleggja og/eða veita þjónustu til fatlaðs fólks.

Sá hluti rannsóknarinnar sem þér býðst að taka þátt í felur í sér rýnihópaumræður með fólki sem starfar við að skipuleggja og/eða veita þjónustu til fatlaðs fólks á Akureyri. Tengiliður hjá Búsetudeild Akureyrarbæjar aðstoðaði við að bera kennsl á mögulega þátttakendur. Við erum að leita eftir einstaklingum sem hafa að minnsta kosti tveggja ára reynslu af því að skipuleggja og/eða veita þjónustu til fatlaðs fólks á Akureyri og sem hefur vegna starfs síns reynslu af því að vera í beinum samskiptum við fatlað fólk.

Í rýnihópnum verður rætt um það hvernig þjónusta, aðstoð, stefna stjórnvalda og aðrir stjórnsýslulegir þættir geti auðveldað fólki með hreyfihamlanir að komast á milli staða í samfélaginu. Þú verður einnig beðin/n um að svara stuttum spurningalista sem veitir rannsakendum viðbótarupplýsingar til að fá betri innsýn í samsetningu hópsins og reynslu hans. Í spurningalistanum verður spurt um þætti er tengjast starfi þínum í þágu fatlaðs fólks

Bls 1/3

Dagsetning

Upphafsstafir þátttakanda

á Akureyri og menntun. Áætlað er að hópurinn samanstandi af 3-5 einstaklingum og að umræðan taki 1-2 klukkustundir. Umræðan mun fara fram á Akureyri (nánari staðsetning ákveðin síðar).

Umræðan verður hljóðrituð og síðan afrituð. Nafnleyndar verður gætt í öllum skrifum sem tengjast rannsókninni. Undirritaðar hafa einar aðgang að þeim upplýsingum sem þátttakendur veita. Farið verður með allar upplýsingar sem trúnaðarmál og þess vandlega gætt að ekki verði hægt að rekja þær. Ekki er hægt að tryggja nafnleynd innan hópsins þar sem miklar líkur eru á að þátttakendur þekki til hvers annars. Athugið að þátttakendum ber að gæta fyllsta trúnaðar varðandi upplýsingar sem tengjast öðrum meðlimum hópsins. Við úrvinnslu gagna verður hluti þeirra þýddur yfir á ensku.

Þátttakendum verður einnig boðið að veita samþykki fyrir að haft verði samband við þá aftur símleiðis eða gegnum tölvupóst meðan á gagnagreiningu stendur til að koma með athugasemdir við grunniðurstöður.

**Það er undir þér komið hvort þú samþykkir þátttöku. Einnig er þér frjálst að hætta þáttöku á hvaða stigi sem er án útskýringa eða nokkurra afleiðinga.**

Þú munt ekki hagnast beint af rannsókninni sjálf/ur, en þátttaka þín er framlag sem getur nýst við skipulag og framkvæmd þjónustu við fatlað fólk. Niðurstöður rannsóknarinnar geta einnig nýst við frekari rannsóknir á áhrifum stjórnsýslulegra þátta á samfélagsþátttöku fatlaðs fólks. Engir þekktir áhættuþættir fylgja því að taka þátt í þessari rannsókn. Rannsóknin hefur fengið leyfi Vísindasiðanefndar og verið tilkynnt til Persónuverndar.

**Fyllsta trúnaðar verður gætt varðandi allar upplýsingar sem aflað verður í rannsókninni.**

Farið verður með persónuupplýsingar og skráningu þeirra í samræmi við lög nr. 77/2000 um persónuvernd og meðferð persónuupplýsinga. Allar upplýsingar sem gefnar verða í viðtölum verða geymdar í rafrænum skráum sem varðar eru með lykilorði. Allt efni verður svo vistað undir dulkóðun á fartölvu áður en það verður flutt frá Íslandi til Kanada. Engin persónueinkenni verða geymd með gögnunum. Gögn á pappírformi verða ávallt geymd í



læstum hirslum. Frumgögnum, ljósritum og tölvugögnum sem fela í sér persónueinkenni verður eytt að rannsókn lokinni og eigi síðar en haustið 2020.

Niðurstöður rannsóknarinnar verða kynntar við doktorsvörn rannsakanda við Western Háskóla í Kanada, ásamt því að stefnt er að því að gera grein fyrir helstu niðurstöðum á því stjórnsýslustigi á Íslandi sem niðurstöðurnar tengjast. Ennfremur kunna niðurstöður að verða nýttar við greinaskrif í fagtímarit. Þátttakendur geta einnig fengið sendar til sín meginniðurstöður ef þeir óska þess.

Með virðingu og vinsemd,

\_\_\_\_\_  
Dr. Snæfríður Þóra Egilson, prófessor við  
Félagsvísindasvið Háskóla Íslands.  
Netfang: sne@hi.is

\_\_\_\_\_  
Sigrún Kristín Jónasdóttir,  
doktorsnemi við Western  
Háskóla, London, Ontario,  
Kanada.

\_\_\_\_\_  
Dr. Jan Polgar, prófessor við Western  
Háskóla, London, Ontario, Kanada.

*Ef þú hefur spurningar um rétt þinn sem þátttakandi í vísindarannsókn eða vilt hætta þátttöku í rannsókninni getur þú snúið þér til Vísindasiðanefndar, Hafnarhúsinu, Tryggvagötu 17, 101 Reykjavík. Sími: 551-7100, fax: 551-1444, tölvupóstfang: vsn@vsn.is.*

*Þetta eintak er fyrir þig til að geyma*

## Appendix I: Information letter for service providers – English



### ***Governance factors support for community mobility: People with mobility limitations in Akureyri***

Principal investigator: Dr. Snæfríður Þóra Egilson, professor at faculty of Social Sciences, University of Iceland, [REDACTED]

The purpose of this letter is to invite you to participate in a focus group discussion which is part of the study: *Governance factors support for community mobility: People with mobility limitations in Akureyri*. The study is a project within Sigrún Kristín Jónasdóttir's doctoral program in Health and Rehabilitation Sciences at Western University, London, Ontario, Canada. The aim of the study is to shed light on how governance factors can support people with mobility limitations to go between places within the community. These factors will be examined from perspective of people with mobility limitations, as well as people that have experience of planning and/or providing services to disabled people.

The part of the study that you are invited to participate in includes focus group discussion with people that work in planning and/or providing services to disabled people in Akureyri. A contact person in the department of residence within the municipal of Akureyri (Búsetudeild) assisted in identifying potential participants. We are looking for individuals who have at least two years experience of planning and/or providing services to people with disabilities in Akureyri and have experience from their work of interacting with people with disabilities.

The focus group will discuss how services, support, governmental policies and other governance factors can make it easier for people with mobility limitations to go between places in the community. You will also be asked to answer short questionnaire that gives the researchers additional information to get better insight into the composition of the group

Bls 1/3

Date

Participant initials

\_\_\_\_\_

\_\_\_\_\_

and its experience. Questions in the questionnaire will ask about factors that relate to your work with disabled people in Akureyri and your education. Estimated number of participants in the group is 3-5 persons and the discussion will take 1-2 hours. The discussion will take place in Akureyri (exact location to be decided later)

The discussion will be audio recorded and transcribed. Only the research team will have access to information that participants give. Anonymity will be ensured in all writings related to the study. All information will be treated as confidential and care will be taken so they are untraceable. Anonymity within the group cannot be guaranteed because the likelihood of participants being familiar with each other. Please note that participants should maintain confidentiality regarding any information related to other members of the group. During data analysis, part of the data will be translated into English.

After the discussion, participants will be invited to give their consent for researchers to contact them again through telephone or email during the data analysis process to provide feedback on primary results.

**It is up to you whether you accept participation. Also you are free to withdraw from the study at any stage without explanation or any consequences.**

You will not benefit directly from the research, but your participation can be a useful contribution for planning and implementing services for disabled people. Results from the study can also be useful for further research on governance factors impact on participation in the society for disabled people. There are no known risk factors in taking part in this study. The study has been approved by the National Bioethics Committee of Iceland and reported to the Data Protection Authority.

Complete confidentiality will be maintained regarding all information that will be obtained in the study. Personal information will be treated and registered in accordance with Act. 77/2000 on Personal Data Protection and Privacy. All data from the interviews will be in password-protected files stored on an encrypted laptop before it will be transferred from

BIs 2/3

Date

Participant initials

\_\_\_\_\_

\_\_\_\_\_

Iceland to Canada. No personal identifiers will be stored with the data. Electronic files will only be shared between members of the research team. Printed documents will be stored in locked cabinets at all times. Original documents, photocopies and computer data that include personal information will be destroyed after the study and no later than the fall of 2020.

Result from this study will be presented when the student, Sigrún Kristín Jónasdóttir, will defend her dissertation at Western University in Canada. Also the aim is to present the main results at relevant administrative level in Iceland. Furthermore, results may be used in articles in profession journals. Participants can also receive summary of findings if they wish.

With respect and kindness,

\_\_\_\_\_  
Dr. Snæfriður Þóra Egilson, professor in the  
Faculty of Social Science, University of  
Iceland

\_\_\_\_\_

\_\_\_\_\_  
Sigrún Kristín Jónasdóttir, Doctoral  
student at Western University,  
London, Ontario, Canada.

\_\_\_\_\_

\_\_\_\_\_  
Dr. Jan Polgar, professor at Western  
University, London, Ontario, Canada. email:

\_\_\_\_\_

*If you have any questions about your rights as a research participant or if you want to withdraw from the study you may contact the office of the national ethics board, Tryggvagata 17, 101 Reykjavík. Telephone: 551-7100, fax: 551-1444, email: vsn@vsn.is*

*This letter is yours to keep for future reference.*

Bls 3/3

Date

\_\_\_\_\_

Participant initials

\_\_\_\_\_

## Appendix J: Informed consent – Icelandic



**Stuðningur af stjórnýslulegum þáttum til að fara á milli staða í samfélaginu: Fólki með hreyfihamlanir á Akureyri.**

### Upplýst samþykki

Ég undirrituð/aður hef lesið og fengið afhent kynningarbréf um þátttöku í rýnihópaumræðum vegna rannsóknarinnar *Stuðningur af stjórnýslulegum þáttum til að fara á milli staða í samfélaginu: Fólki með hreyfihamlanir á Akureyri*. Rannsóknin er hluti af doktorsverkefni Sigrúnar Kristínar Jónasdóttur í heilbrigðis- og endurhæfingarvísindum við Western Háskóla, London, Ontario, Kanada. Ábyrgðarmaður rannsóknarinnar er Dr. Snæfríður Þóra Egilson, prófessor við Háskóla Íslands.

Þátttakan felur í sér að taka þátt í umræðum um hvernig þjónusta, aðstoð, stefna stjórnvalda og aðrir stjórnýslulegir þættir geti auðveldað fólki með hreyfihamlanir að komast á milli staða í samfélaginu.

Farið verður með allar upplýsingar sem trúnaðarmál og þess vandlega gætt að ekki verði unnt að rekja þær.

Ég samþykki hér með að taka þátt í rannsókninni eins og henni er lýst í kynningarbréfi. Eðli rannsóknarinnar hefur verið útskýrt fyrir mér og ég hef fengið fullnægjandi svör við öllum mínum spurningum tengdum rannsókninni. Mér er frjálst að hætta þátttöku í rannsókninni á hvaða stigi hennar sem er.

\_\_\_\_\_  
Nafn þátttakanda

\_\_\_\_\_  
Staður og dagsetning

\_\_\_\_\_  
Undirskrift þátttakanda

\_\_\_\_\_  
Undirskrift rannsakanda, til staðfestingar að upplýst samþykkis hafi verið aflað

## Appendix K: Informed consent – English



### ***Governance factors support for community mobility: People with mobility limitations in Akureyri.***

#### **Informed consent**

I have read and received a copy of information letter on participation in focus group discussion for the study *Governance factors support for community mobility: People with mobility limitations in Akureyri*. The study is part of Sigrún Kristín Jónasdóttir's doctoral project within Health and Rehabilitation Sciences at Western University, London, Ontario, Canada. Principal investigator is Snæfríður Þóra Egilson, professor at University of Iceland.

Participants will take part in discussion about how services, support, governmental policies and other governance factors can make it easier for people with mobility limitations to go between places in the community.

All information will be treated as confidential and care will be taken so they are untraceable

**I hereby agree to participate in the study as described. The nature of the study has been explained to me and I have received satisfactory answers to all my questions related to the study. I am free to withdraw from the study at any stage.**

\_\_\_\_\_  
*Participant's name*

\_\_\_\_\_  
*Place and date*

\_\_\_\_\_  
*Participant's signature*

\_\_\_\_\_  
*Researcher's signature, certifying that informed consent has been obtained*

## Appendix L: Introduction – service users – Icelandic

Verið þið velkomin og bestu þakkir fyrir að gefa ykkur tíma til þess að taka þátt í þessum umræðum. Ég heiti Sigrún og er í doktorsnámi í heilbrigðis- og endurhæfingarvísindum við Western Háskóla, London, Ontario, Kanada.

Ykkur er öllum boðið að taka þátt vegna þess að þið eigið það sameiginlegt að nota hjólastól eða göngugrind daglega.

Það sem við ætlum að ræða um í dag er hvernig þjónusta og aðstoð sem og stefna stjórnvalda og aðrir stjórnsýslulegir þættir geti auðveldað ykkur að komast um í samfélaginu. Ég vil halda þessu eins og opnu og hægt er og fá upp öll möguleg atriði sem þið teljið að hafi áhrif á möguleika ykkar til að komast frá einum stað til annars og er skaffað eða stjórnað af stefnu stjórnvalda, ákvörðunum eða starfsemi. Ég vil gjarnan heyra um þætti sem tengjast því að komast á milli staða gangandi eða á hjólastól, en líka í einhverju ökutæki t.d. eigin bíl, strætó, ferðaþjónustu o.s.frv.

Það eru engin rétt eða röng svör. Þið getið haft mismunandi skoðanir og ég vil gjarnan heyra frá ykkur öllum. Það væri gott ef einungis einn talar í einu.

Umræðurnar eru teknar upp vegna þess að ég vil ekki missa af eða gleyma einhverju af því sem þið komið á framfæri. Nöfnin ykkar munu ekki koma fram í neinu sem skrifað verður upp úr þessum umræðum.

Við erum með nafnspjöld fyrir framan okkur sem geta auðveldað okkur öllum að muna nöfn hvers annars. Ef þið hafið eitthvað sem þið viljið koma á framfæri eða fylgja einhverju eftir sem hefur verið rætt þá endilega gerið það. Mitt hlutverk hér í dag er að spyrja spurninga, hlusta og sjá til þess að allir fái tækifæri til að tjá sig.

Mig langar að biðja ykkur um að slökkva á hljóðinu í farsímunum ykkar og svo getum við byrjað.

## **Appendix M: Introduction – service users – English**

### ***Governance factors support for community mobility: People with mobility limitations in Akureyri***

Welcome and best of thanks for giving your time to take part in this discussion. My name is Sigrún and I am in a doctoral program in Health and Rehabilitation Sciences at Western University, London, Ontario, Canada.

You are all invited to participate because you have in common that you use wheelchair or walker on a daily basis.

What we are going to discuss today is how services, support, governmental policies and other governance factors can make it easier for people with mobility limitations to get around in the community. I want to keep the discussion as open as possible and get every possible factor that you consider to affect your chance of getting from one place to another, and that is provided or controlled by governmental policies, decisions and activities. I would like to hear about aspects related to getting around on foot or in a wheelchair, but also in vehicles such as own car, bus, special transportation services, etc.

There are no right or wrong answers. You can have different opinions and I would like to hear from you all. Please make sure only one person speaks at a time.

The discussion will be recorded because I do not want to miss or forget any of your comments. Your names will not appear in any writings from this discussion.

We have name tents in front of us that can help us all to remember each other's names. If you have something that you want to say or follow up on something that has been said, feel free to do that. My role here is to ask questions, listen and make sure everyone has a chance to share.

I would like to ask you to turn off the sound on your mobile phones and then we can start.



## Appendix N: Question guide – service users – Icelandic



HÁSKÓLI ÍSLANDS

Vegna rannsóknarinnar:

*Stuðningur af stjórnsýslulegum þáttum til að fara á milli staða í samfélaginu: Fólk með hreyfihamlanir á Akureyri*

### Spurningar fyrir rýnihópaviðtal – hópur A

Þið eigið öll sameiginlegt að nota einhverskonar hjálpartæki eins og hjólastól, rafmagnshjólastól eða göngugrind. Í dag, þá langar mig að heyra af reynslu ykkar af því að komast frá einum stað til annars í samfélaginu.

Hver er ykkar reynsla af því að fara á milli staða í samfélaginu?

- Hvernig komist þið á milli staða?
- Hvert er mikilvægt fyrir ykkur að komast?
- Eru einhverjir staðir sem eru ykkur mikilvægir sem þið komist ekki á?
- Hvaða áhrif hefur það á ykkur ef þið komist ekki milli staða?
- Hvernig hefur það að komast á milli staða áhrif á það sem þið gerið eða gerið ekki?
- Hvað er það sem hefur áhrif á að þið komist þangað sem þið viljið fara í samfélaginu?
- Hvað myndi auðvelda ykkur að komast á milli staða?
  - T.d. þjónusta, aðgengismál, önnur úrræði, fjárframlög/styrkir, annað.

Ímyndið ykkur að það sé eitthvað um að vera niður í bæ á Akureyri sem þið viljið taka þátt í.

- Hvernig mynduð þið fara þangað?
- Hvað hefur áhrif á ákvörðun ykkar um að fara þangað með þeim hætti

- Hvað auðveldar ykkur förina?
- Hvað gerir ykkur erfiðara fyrir?

Segjum sem svo að nú sé eitthvað um að vera í samfélaginu utan við Akureyri (t.d. á Dalvík, í Varmahlíð eða Mývatnssveit).

- Hvernig mynduð þið fara þangað?
- Hvað hefur áhrif á ákvörðun ykkar um að fara þangað með þeim hætti
- Hvað auðveldar ykkur förina?
- Hvað gerir ykkur erfiðara fyrir ?

Í þessum dæmum sem hafa verið rædd, hvernig hefur tímasetning áhrif á það að komast á milli staða?

- Munur á degi, kvöldi, virkum dögum, helgar, o.s.frv.
- Árstíðabundnir þættir s.s. veðurfar, snjór, hálka o.s.frv.

Nú skulum við gera okkur í hugarlund að þið takið þátt í nefnd sem er að þróa þjónustu og stefnu til að stuðla að því að fólk með hreyfihamlanir komist á milli staða í samfélaginu.

- Hvað þyrfti nefndin að hafa í huga til að koma þessu til leiðar?
  - Athugið: Þetta getur tengst beint þjónustu, en einnig kerfinu sem heild og stefnu stjórnvalda og regluverkinu.
  - Hvernig sjáið þið fyrir ykkur að hægt væri að auðvelda ykkur að komast á milli staða?

## Appendix O: Question guide – service users - English



The study:

*Governance factors support for community mobility: People with mobility limitations in Akureyri*

### Questions for focus group A

You all have in common that you use some kind of mobility device, for example wheelchair, powered wheelchair or walker. Today, I want to hear about your experience of going from one place to another in the community.

What is your experience of going between places in the community?

- How do you go between places today?
  
- Where is important for you to go?
- Are there some places that are important for you that you are not able to go to?
  
- What effect does it have for you if you are not able to go between places?
- How does going between places affect what you do or do not do?
  
- What is it that affects that you can go to places that you want to go to in the community?
- What would make it easier for you to go between places?
  - For example, services, accessibility, other resources, funding, other.

Imagine there is something going on downtown Akureyri that you want to participate in.

- How would you go there?
- What affects your decision to travel that way?

- What makes the trip easier?
- What makes the trip harder?

Suppose that now something is going on in the community outside of Akureyri (for example in Dalvík, Varmahlíð or Mývatnssveit).

- How would you go there?
- What affects your decision to travel that way?
- What makes the trip easier?
- What makes the trip harder?

For both these examples discussed, how does timing affect the ability to go between places?

- Difference between day, evening, workday, weekends etc.
- Seasonal factors such as weather, snow, ice etc.

Now, imagine you were a part of a committee that is developing services and policies to support community mobility for people that use mobility limitations.

What does the committee need to have in mind to achieve this?

- Note: this can be directly related to the services, but also the whole system and policies, regulations etc.
- How would you imagine it to be made easier for you to go between places?

## Appendix P: Introduction – service providers – Icelandic

Verið þið velkomin og bestu þakkir fyrir að gefa ykkur tíma til þess að taka þátt í þessum umræðum. Ég heiti Sigrún og er í doktorsnámi í heilbrigðis- og endurhæfingárvísindum við Western Háskóla, London, Ontario, Kanada.

Ykkur er öllum boðið að taka þátt vegna þess að þið eigið það sameiginlegt að hafa reynslu af því að veita og/eða skipuleggja þjónustu fyrir fatlað fólk og að vera í beinum samskiptum við fatlað fólk.

Það sem við ætlum að ræða um í dag er hvernig þjónusta og aðstoð, sem og stefna stjórnvalda og aðrir stjórnsýslulegir þættir geti auðveldað fólki með hreyfihamlanir að komast um í samfélaginu. Ég vil halda þessu eins opnu og hægt er og fá upp öll möguleg atriði sem þið teljið að hafi áhrif á möguleika fólks með hreyfihamlanir til að komast frá einum stað til annars og er skaffað eða stjórnað af stefnu stjórnvalda, ákvörðunum eða starfsemi. Ég vil gjarnan heyra um þætti sem tengjast því að komast á milli staða gangandi eða á hjólastól, en líka í einhverju ökutæki t.d. eigin bíl, strætó, ferðaþjónustu o.s.frv.

Það eru engin rétt eða röng svör. Þið getið haft mismunandi skoðanir og ég vil gjarnan heyra frá ykkur öllum. Það væri gott ef einungis einn talar í einu.

Umræðurnar eru teknar upp vegna þess að ég vil ekki missa af eða gleyma einhverju af því sem þið komið á framfæri. Nöfnin ykkar munu ekki koma fram í neinu sem skrifað verður upp úr þessum umræðum.

Við erum með nafnspjöld fyrir framan okkur sem getur auðveldað okkur öllum að muna nöfn hvers annars. Ef þið hafið eitthvað sem þið viljið koma á framfæri eða fylgja einhverju eftir sem hefur verið rætt þá endilega gerið það. Mitt hlutverk hér í dag er að spyrja spurninga, hlusta og sjá til þess að allir fái tækifæri til að tjá sig.

Mig langar að biðja ykkur um að slökkva á hljóðinu í farsímunum ykkar og svo getum við byrjað.

## Appendix Q: Introduction – service providers – English

### *Governance factors support for community mobility: People with mobility limitations in Akureyri*

Welcome and best of thanks for giving your time to take part in this discussion. My name is Sigrún and I am in a doctoral program in Health and Rehabilitation Sciences at Western University, London, Ontario, Canada.

You all are invited to participate because you have in common the experience of providing and/or planning services for disabled people and having direct interaction with disabled people.

What we are going to discuss today is how services, support, governmental policies and other governance factors can make it easier for people with mobility limitations to get around in the community. I want to keep the discussion as open as possible and get every possible factor that you consider to affect your chance of getting from one place to another, and that is provided or controlled by governmental policies, decisions and activities. I would like to hear about aspects related to getting around on foot or in a wheelchair, but also in vehicles such as own car, bus, special transportation services, etc.

There are no right or wrong answers. You can have different opinions and I would like to hear from you all. It would be good if only one speaks at a time.

The discussion will be recorded because I do not want to miss or forget any of your comments. Your names will not appear in any writings from this discussion.

We have name tents in front of us that can help us all to remember each other's names. If you have something that you want to say or follow up on something that has been said, feel free to do that. My role here is to ask questions, listen and make sure everyone has a chance to share.

I would like to ask you to turn off the sound on your mobile phones and then we can start.

8 Oct. 14

## Appendix R: Question guide – service providers – Icelandic



Vegna rannsóknarinnar:

*Stuðningur af stjórnsýslulegum þáttum til að fara á milli staða í samfélaginu: Fólk með hreyfihamlanir á Akureyri*

### Spurningar fyrir rýnihópaviðtal – hópur B

Þið hafið öll sameiginlegt að hafa reynslu af því að starfa með fötluðu fólki. Að þessu sinni ætlum við sérstaklega að beina sjónum að fólki sem notar hjólastóla, rafmagnshjólastóla eða göngugrindur.

Til að byrja með væri gaman að heyra aðeins hver ykkar reynsla er hvað þessi mál varðar af því að starfa með fólki með hreyfihamlanir?

Af samkiptum ykkar við þennan hóp, hver er ykkar upplifun á því hvernig þeim gengur að komast á milli staða í samfélaginu?

- Teljið þið að þau séu að komast allt sem þau þurfa og vilja fara? Ef ekki hvert komast þau ekki?
- Hvað er það sem hefur áhrif á að þau komist þangað sem þau vilja fara í samfélaginu?
- Hvaða val teljið þið að þau hafi um hvernig þau fari milli staða?
- Hvernig er að fara á milli staða innanbæjar?
- Hvernig er að fara á milli staða utanbæjar?
- Hvernig hefur tímasetning áhrif á það að komast á milli staða? (munur á degi, kvöldi, virkum dögum, helgar, o.s.frv. og árstíðabundnir þættir s.s. veðurfar, snjór, hálka o.s.frv.)

Ímyndið ykkur að þið takið þátt í nefnd sem er að þróa þjónustu og stefnu til að stuðla að því að fólk með hreyfihamlanir komist á milli staða í samfélaginu.

- Hvað þyrfti nefndin að hafa í huga til að koma þessu til leiðar?
  - Athugið: Þetta getur tengst beint þjónustu, en einnig kerfinu sem heild og stefnu stjórnvalda og regluverkinu.
  - Hvernig sjáið þið fyrir ykkur að hægt væri að auðvelda þessum hóp að komast á milli staða?
  - Hvernig getur kerfið, stefna stjórnvalda, lög, reglugerðir o.s.frv. betur stutt við þjónustu fyrir þennan hóp, í tengslum við að komast á milli staða?

## Appendix S: Question guide – service providers – English



### The study:

*Governance factors support for community mobility: People with mobility limitations in Akureyri*

### **Question for focus group B**

You all have in common that you have experience of working with disabled people. Today we are especially focusing on people that use wheelchairs, powered wheelchairs or walkers.

To begin with, it would be nice to hear a bit about your experience of these issues from working with people with mobility limitations?

From your interaction with this group, what is your experience on how things are for them when going between places within the community?

- Do you think they can go everywhere that they need to and want to go? If not where are they not able to go?
- What is it that affects that they can go where they want to in the community?
- What choice do you think they have about how they go between places?
- How is it to go between places within Akureyri?
- How is it to go between places outside Akureyri?
- How does timing affect the ability to go between places? (difference between day, evening, workday, weekends etc. and seasonal factors such as weather, snow, ice etc.)

Now, imagine you were a part of a committee that is developing services and policies to support community mobility for people with mobility limitations. What does the committee need to have in mind to achieve this?

- Note: this can be directly related to the services, but also the whole system and policies, regulations etc.
- How would you imagine it to be made easier for this group to go between places?
- How can the system, governmental policies, laws, regulations etc. better support services for this group, in relation to going between places?



## Appendix T: Additional questionnaire – service users – Icelandic

### Viðbótarupplýsingar, spurningalisti

#### Aldur

- 18-24 ára       25-34 ára       35-44 ára       45-54 ára  
 55-64 ára       65-74 ára       75 eða eldri

#### Kyn

- Karl                       Kona

#### Menntun

- Grunnskólapróf  
 Iðnmenntun                       Háskólapróf /grunnám  
 Stúdentspróf                       Háskólapróf /framhaldsnám

#### Stundar þú vinnu?

- Nei  
 Já

Ef já, hvert er starfshlutfall þitt? \_\_\_\_\_%

#### Stundar þú nám?

- Nei  
 Já

Ef já, hvert er námshlutfall þitt? \_\_\_\_\_%

#### Hvernig er heimilishögum þínum háttað (merkið við fleiri en eitt ef við á)

- Bý ein/einn  
 Er í sambúð, gift, kvæntur  
 Bý með barni/börnum (yngri en 18 ára)  
 Bý með barni/börnum (18 ára eða eldri)  
 Bý með foreldri/foreldrum  
 Bý með vini/vinum

#### Notar þú göngugrind?

- Nei  
 Já

**Notar þú hjólastól?** Nei Já**Ef já, hvort notar þú handknúinn eða rafdrifinn hjólastól?** Handknúinn Rafdrifinn Bæði**Hversu langa reynslu hefur þú af að nota hjólastól eða göngugrind?** 1-2 ár 2-5 ár 5-10 ár Meira en 10 ár**Hvernig ferðu á milli staða í samfélaginu?** Ek sjálf/ur Nýti mér almenningssamgöngur Nýti mér sérskipulagðar ferðir Mér er ekið Fer um gangandi eða á hjólastól Annað \_\_\_\_\_**Hversu oft í viku (að meðaltali) ferðu út í samfélagið vegna vinnu eða náms?** Aldrei 1-3 í viku 4-6 í viku 7-9 í viku 10 í viku eða oftar

**Hversu oft í viku (að meðaltali) ferðu út í samfélagið til að sinna erindum fyrir heimilið (t.d. versla inn, fara í banka o.s.frv.)?**

- |                                     |  |
|-------------------------------------|--|
| <input type="checkbox"/> Aldrei     | <input type="checkbox"/> 7-9 í viku          |
| <input type="checkbox"/> 1-3 í viku | <input type="checkbox"/> 10 í viku eða oftar |
| <input type="checkbox"/> 4-6 í viku |  |

**Hversu oft í viku (að meðaltali) ferðu út í samfélagið til að sinna áhugamálum eða gera eitthvað þér til ánægju?**

- |                                     |  |
|-------------------------------------|--|
| <input type="checkbox"/> Aldrei     | <input type="checkbox"/> 7-9 í viku          |
| <input type="checkbox"/> 1-3 í viku | <input type="checkbox"/> 10 í viku eða oftar |
| <input type="checkbox"/> 4-6 í viku |  |

**Hversu oft í viku (að meðaltali) ferðu út í samfélagið til að heimsækja vini eða ættingja?**

- |                                     |  |
|-------------------------------------|--|
| <input type="checkbox"/> Aldrei     | <input type="checkbox"/> 7-9 í viku          |
| <input type="checkbox"/> 1-3 í viku | <input type="checkbox"/> 10 í viku eða oftar |
| <input type="checkbox"/> 4-6 í viku |  |

**Upplifir þú einhverjar hindranir við það að komast á milli staða í samfélaginu?**

- Já                       Nei

**ef já, nefndu allt að þrjá þætti sem þú telur hindra þig í að komast á milli staða í samfélaginu**

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## Appendix U: Additional questionnaire – service users – English

### *Governance factors support for community mobility: People with mobility limitations in Akureyri*

#### Additional information

##### Age

- 18-24 years       25-34 years       35-44 years       45-54 years  
 55-64 years       65-74 years       75 or older

##### Gender

- male                       female

##### Education

- Secondary school  
 Technical skills / vocational education       University degree (undergraduate)  
 Matriculation examination                       University degree (postgraduate)

##### Do you work?

- No  
 Yes  
 If yes, how much (full-time, part-time, %) ? \_\_\_\_\_

##### Do you attend school?

- No  
 Yes  
 If yes, how much (full-time, part-time, %) ? \_\_\_\_\_

##### How are your circumstances at home (tick more than one if applicable)

- Live alone  
 Married or common-law partnership  
 Live with child/children (younger than 18 years)  
 Live with child/children (18 years or older)  
 Live with parent/parents  
 Live with friend/friends

##### Do you use a walker?

- No  
 Yes

**Do you use a wheelchair?**

- No  
 Yes

**If yes, do you use manual or powered wheelchair?**

- Manual  
 Powered  
 Both

**How long experience do you have of using wheelchair or walker?**

- 1-2 years  
 2-5 years  
 5-10 years  
 More than 10 years

**How do you go between places within the community?**

- Drive myself  I am driven  
 Use public transport  Other \_\_\_\_\_  
 Use special transportation services \_\_\_\_\_

**How long experience do you have using a wheelchair or a walker?**

- 1-2 years  5-10 years  
 2-5 years  More than 10 years

**How many times a week (on average) do you go out in the community for work or school?**

- Never  
 1-3 a week  
 4-6 a week  
 7-9 a week

10 a week or more

**How many times a week (on average) do you go out in the community to run errands for the home (groceries, go to the bank, etc.)?**

Never

1-3 a week

4-6 a week

7-9 a week

10 a week or more

**How many times a week (on average) do you go out in the community for leisure activities or simply for pleasure?**

Never

1-3 a week

4-6 a week

7-9 a week

10 a week or more

**How many times a week (on average) do you go out in the community to visit friends or family?**

Never

1-3 a week

4-6 a week

7-9 a week

10 a week or more

**Do you experience any barriers on going between places in the community?**

Yes

No

**If yes, mention up to three factors that you consider barriers for you to go between places in the community**

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## Appendix V: Additional questionnaire – service providers – Icelandic

### Viðbótarupplýsingar

#### Aldur

- 18-24 ára       25-34 ára       35-44 ára       45-54 ára  
 55-64 ára       65-74 ára       75 eða eldri

#### Kyn

- Karl                       Kona

#### Menntun

- Grunnskólapróf                       Háskólapróf /grunnám  
 Iðnmenntun                       Háskólapróf /framhaldsnám  
 Stúdentspróf                       Háskólapróf /framhaldsnám

Á hvaða sviði er menntun þín (t.d. iðjuþjálfun, félagsráðgjöf, kennari, annað)

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Við hvað starfar þú?

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Hversu langa reynslu hefur þú af að skipuleggja og/eða veita þjónustu til fatlaðs fólks?

- 1-2 ár  
 2-5 ár  
 5-10 ár  
 Meira en 10 ár

**Hversu oft í viku (að meðaltali) ertu í beinum samskiptum við fatlað fólk vegna vinnu þinnar?**

- Aldrei
- Nokkrum sinnum í mánuði
- Nokkrum sinnum á viku
- Daglega

**Hversu oft í viku (að meðaltali) ertu í beinum samskiptum við fólk með hreyfihamlanir (sem notar hjólastól, rafmagnshjólastól eða göngugrind) vegna vinnu þinnar?**

- Aldrei
- Nokkrum sinnum í mánuði
- Nokkrum sinnum á viku
- Daglega

**Telur þú að til staðar séu einhverjar hindranir við það að komast á milli staða í samfélaginu fyrir fólk með hreyfihamlanir á Akureyri?**

- Já
- Nei

**ef já, nefndu allt að þrjá þætti sem þú telur hindra fólk með hreyfihamlanir í að komast á milli staða í samfélaginu**

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## Appendix W: Additional questionnaire – service providers – English

*Governance factors support for community mobility: People with mobility limitations in Akureyri*

### Addition information

#### Age

- 18-24 years       25-34 years       35-44 years       45-54 years  
 55-64 years       65-74 years       75 years or older

#### Gender

- Male                       Female

#### Education

- Secondary school  
 Technical skills / vocational education       University degree (undergraduate)  
 Matriculation examination                       University degree (postgraduate)

**In what field is your education (for example Occupational Therapy, Social Work, Teacher, other)**

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**What is your professional designation?**

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**How long experience do you have of planning and/or providing service to disabled people?**

- 1-2 years     5-10 years  
 2-5 years     More than 10 years

**How many times a week (on average) are you in direct interaction with disabled people in your work?**

- Never  
 Several times a month

- Several times a week
- Every day

**How many times a week (on average) are you in direct interaction with people with mobility limitations (that use wheelchair, powered wheelchair or walker) in your work?**

- Never
- Several times a month
- Several times a week
- Every day

**Do you think that people with mobility limitation experience any barriers on going between places in the community?**

- Yes
- No

**If yes, mention up to three factors that you consider barriers for people with mobility limitations to go between places in the community.**

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## Appendix X: Collaboration agreement – gatekeeper for recruitment of service users

Vegna rannsóknarinnar: *Stuðningur af stjórnslulegum þáttum til að fara á milli staða í samfélaginu: Fólk með hreyfihamlanir á Akureyri*

Ábyrgðarmaður: Dr. Snæfríður Þóra Egilson  
Rannsakandi: Sigrún Kristín Jónasdóttir meistaranemi

Ég undirrituð [REDACTED] á Endurhæfingarstöð Sjálfsbjargar á Akureyri, samþykki að vera samstarfsaðili að rannsókninni.

Samstarfið felst í því að hafa milligöngu um að finna einstaklinga til að taka þátt í rýnihópaviðtali. Við munum kynna rannsóknina fyrir væntanlegum þátttakendum og gefa rannsakanda upp nafn, símanúmer og tölvupóstfang þeirra eftir að hafa fengið samþykki þeirra fyrir því deila þeim upplýsingum til rannsakanda.

Akureyri 26/5/2014  
Staður og dagsetning

[REDACTED]

### Translation:

The research: Governance factors support for community mobility: People with mobility limitations in Akureyri

Principal investigator: Dr. Snæfríður Þóra Egilson  
Researcher: Sigrún Kristín Jónasdóttir graduate student

I, [REDACTED] Rehabilitation center of Sjálfsbjörg in Akureyri, agree to be collaborate in the research.

This collaborate consist in assisting finding individuals to participate in focus group interview. We will give potential participants information about the study and give the researcher individual's name, phone number and email after getting his/her permission for sharing that information to the researcher.

## Appendix Y: Collaboration agreement – assistance with identifying potential participants

Vegna rannsóknarinnar: *Stuðningur af stjórnsýslulegum þáttum til að fara á milli staða í samfélaginu: Fólki með hreyfihamlaðir á Akureyri*

Ábyrgðarmaður: Dr. Snæfríður Þóra Egilson  
Rannsakandi: Sigrún Kristín Jónasdóttir meistaranemi

Ég undirrituð, [REDACTED] samþykki að vera samstarfsaðili að rannsókninni.

Samstarfið felst í því að aðstoða rannsakanda við að bera kennsl á mögulega þátttakendur (einstaklinga sem hafa reynslu af því að skipuleggja eða veita þjónustu til fólks með fatlanir) fyrir rýnihópaviðtal. Rannsakandi sjálfur mun svo hafa samband við viðkomandi einstaklinga og bjóða þeim að taka þátt.

*Akureyri 27.05.2014*  
Staður og dagsetning

Translation:

The research: Governance factors support for community mobility: People with mobility limitations in Akureyri

Principal investigator: Dr. Snæfríður Þóra Egilson  
Researcher: Sigrún Kristín Jónasdóttir graduate student

I, [REDACTED] agree to collaborate in the research.

The collaboration consist in assisting with identifying potential participants (individual that have experience of planning and/or providing services to disabled people) for focus group interview. The researcher will then contact potential participants herself via email and invite them to participate.

## Appendix Z: Declaration of approval form – Icelandic

Ég undirrituð/aður gef hér með \_\_\_\_\_, \_\_\_\_\_ á  
 Endurhæfingarstöð Sjálfsbiargar á Akureyri, leyfi til að gefa Sigrúnu Kristínu  
 Jónasdóttur upp nafn mitt, símanúmer og tölvupóstfang í beim tilgangi að Sigrún hafi  
 samband við mig til að veita mér nánari upplýsingar og svara spurningum þeim sem  
 ég kann að hafa varðandi rannsóknina: **Stuðningur af stjórnáslulegum þáttum til að  
 fara á milli staða í samfélaginu: Fólk með hreyfihamlanir á Akureyri**

\_\_\_\_\_  
 Nafn

\_\_\_\_\_  
 Tölvupóstfang

\_\_\_\_\_  
 Símanúmer

\_\_\_\_\_  
 Undirskrift

\_\_\_\_\_  
 Staður og dagsetning

## Appendix AA: Declaration of approval form - English

I hereby give [REDACTED] in the Rehabilitation center of Sjálfsbjörg in Akureyri, permission to give Sigrún Kristín Jónasdóttir my name, phone number and email. The purpose is so Sigrún Kristin Jónasdóttir can contact me to give me further information and answer any question that I might have regarding the study: ***Governance factors support for community mobility: People with mobility limitations in Akureyri***

\_\_\_\_\_  
*Name*

\_\_\_\_\_  
*Email*

\_\_\_\_\_  
*Phone number*

\_\_\_\_\_  
*Signature*

\_\_\_\_\_  
*Place and date*

## Appendix BB: Permission from Journal of Occupational Science to include published articles

From: Clare Hocking [REDACTED]  
 Subject: RE: Permission to Use Copyrighted Material in a Doctoral Thesis  
 Date: 2. janúar 2019 kl. 17:14  
 To: Sigrun Kristin Jonasdottir [REDACTED]

CH

Dear Sigrún

**Thank you for your request and for the detailed information about access that will be available to your publications in JOS via your institutional library and other means. I am pleased to grant copy right permission to include the articles specified in your thesis, conditional on full attribution as provided in your email message**

Regards  
 Clare

---

**From:** Sigrun Kristin Jonasdottir [REDACTED]  
**Sent:** Thursday, 3 January 2019 8:10 AM  
**To:** Clare Hocking [REDACTED]  
**Subject:** Permission to Use Copyrighted Material in a Doctoral Thesis

Dear Dr. Hocking

I am writing to request permission to include the following material in my Doctoral thesis entitled "Services, systems and policies shaping community mobility for people with mobility impairments: A case study from northern Iceland"

**Sigrún Kristín Jónasdóttir, Carri Hand, Laura Misener & Jan Polgar (2018): Applying case study methodology to occupational science research, Journal of Occupational Science, DOI: 10.1080/14427591.2018.1480409**

**Sigrún Kristín Jónasdóttir, Snæfríður Þóra Egilson & Jan Polgar (2018): Services, systems, and policies affecting community mobility for people with mobility impairments in Northern Iceland: An occupational perspective, Journal of Occupational Science, DOI: 10.1080/14427591.2018.1474797**

My thesis will be available in full-text on the internet for reference, study and / or copy. Except in situations where a thesis is under embargo or restriction, the electronic version will be accessible through the Western Libraries web pages, the Library's web catalogue, and also through web search engines. I will also be granting Library and Archives Canada and ProQuest/UMI a non-exclusive license to reproduce, loan, distribute, or sell single copies of my thesis by any means and in any form or format. These rights will in no way restrict republication of the material in any other form by you or by others authorized by you.

The material will be attributed through a citation.

Please confirm in writing or by email that these arrangements meet with your approval.

Sincerely

**Sigrún Kristín Jónasdóttir**

BSc(OT), OT Reg. (IS), PhD Student,

Graduate Program in Health and Rehabilitation Sciences

Field of Occupational Science

Western University





## Appendix CC: Permission to include a published article from the Canadian Journal of Occupational Therapy

From: permissions (US) [REDACTED]  
Subject: RE: Do I need permission to include my article in my PhD thesis?  
Date: 15. janúar 2019 kl. 11:53  
To: Sigrun Kristin Jonasdottir [REDACTED]

P

Dear Sigrún Kristín Jónasdóttir,

Thank you for your email.

You may post the Accepted Version<sup>2</sup> of your article on your own personal website, your department's website or the repository of your institution, Western University any time after publication.

You may post the Accepted Version<sup>2</sup> to a database or repository NOT affiliated with your institution **12 months after publication**.

**NOTE:** Accepted Version<sup>2</sup> is the original submission to the journal with your revisions after peer review, often the version accepted by the editor (author accepted manuscript)

Let me know if you have any further questions.

**Mary Ann Price**  
*Rights Coordinator*  
SAGE Publishing  
2600 Virginia Ave NW, Suite 600  
Washington, DC 20037  
USA

[REDACTED]

Los Angeles | London | New Delhi  
Singapore | Washington DC | Melbourne

## Curriculum Vitae

**Name:** Sigrún Kristín Jónasdóttir

### Post-secondary Education and Degrees

- |                |  |
|----------------|--|
| 2014 – current | University of Western Ontario<br>London, Ontario, Canada<br>PhD Candidate<br>Supervisor: Dr. Jan Polgar  |
| 2013-2014      | The University of Western Ontario<br>London, Ontario, Canada<br>Master's student – advanced into the PhD program<br>Supervisors: Dr Lynn Shaw & Dr. Jan Polgar |
| 2004 - 2008    | University of Akureyri<br>Akureyri, Iceland<br>B.Sc. OT<br>Supervisor: Dr. Snæfríður Þóra Egilson  |
| 2001-2004      | Húsvík College<br>Húsvík, Iceland<br>Matriculation certificate, Natural Science  |

### Scholarships, honours and awards

2014 – 2018	Western Graduate PhD Research Scholarship, total \$97.142 CAD
2017	Faculty of Health Sciences Graduate Student Travel Award \$260 CAD
2017	Health and Rehabilitation Science Graduate Student Travel Award \$400 CAD
2015	Was nominated by Western University to the national competition for the Vanier Canada Graduate Scholarship
2015	Faculty of Health Sciences Graduate Student Travel Award \$425 CAD
2015	Health and Rehabilitation Science Graduate Student Travel Award \$500 CAD
2013 – 2014	Western Graduate Masters Research Scholarship \$12.700 CAD
2010	Fellowship with the Eyjafjörður Business Development Agency
2010	Grant for women entrepreneurs in Iceland 300.000 ISK
2008	University of Akureyri – Award for the highest average grade in the Occupational Therapy B.Sc. program

2004 Húsavík College – Dux award for the highest average grade of all graduating students

2004 Húsavík College – Awards for outstanding achievement in Icelandic, German and Danish language studies, as well as Chemistry and Science

### **Teaching experience**

- 2018 - present University of Akureyri, Iceland  
Adjunct  
- Designing, coordinating, and teaching two courses:  
- 1) Focus on the Icelandic welfare system and how it shapes occupation  
- 2) Focus on environmental factors shaping occupation – such as accessibility, assistive technology, and ergonomics
- 2018 Graduate Teaching Assistant – Western University  
- Course: Mental Health in Context  
- Coordinator: Dr. Jessie Wilson
- 2015 Guest lecturer – Western University  
Course OT-9662 – Global and local issues in occupation
- 2015 Guest lecturer – King’s University College  
Course: Social Construction of Disability Cross Culture
- 2014 – 2016 Graduate Teaching Assistant – Western University  
Course: Consolidation of practice knowledge OT 9613  
Coordinator: Dr. Sandi Spaulding

### **Research experience**

- 2015-2018 Graduate Research Assistant  
 - HQP in AGE-WELL, a Canadian Network of Centres of Excellence  
 - Project: CARE RATE: Online Assistive Technology Rating and Recommending System for Caregivers  
 - Project leaders: Dr. Jan Polgar, Dr. Frank Rudzicz & Dr. Jennifer Boger
- 2014 Graduate Research Assistant  
 Ontario Human Capital Research and innovation fund project on Work Transitions Interventions for youth with disabilities.  
 Principal investigator: Dr. Lynn Shaw
- 2014 Western University – Graduate student participant  
 - Project: Canada-Norway partnership project developing case studies to improve student awareness of mobility issues in the high North.

### **Professional experience**

- 2012 - 2013 Vinnuvernd ehf  
 Ergonomic consultant
- 2010 – 2011 Municipality of Akureyri  
 Department head in a residence for disabled people
- 2010 – 2011 Ergon -Ergonomic consulting  
 Owner and ergonomic consultant

- 2008 – 2009 Hospital of Akureyri – Kristnesspítali  
Occupational Therapist at a Rehabilitation center – leader of professional unit within the OT department
- 2005 – 2007 Municipality of Akureyri  
Part-time employment in a residence for disabled people

### **Seminars and workshops**

- 2013 Communication in the Canadian classroom (12 hours)
- 2013 Seminar by the Occupational Safety and Health Authority in Iceland  
-For occupational representatives, emphasising working conditions, health and safety at work (12 hours)
- 2010 Seminar by the Occupational Safety and Health Authority in Iceland  
-Prerequisite to become a certified ergonomic consultant (12 hours)
- 2010 Entrepreneur seminar by the Innovation Center Iceland  
-Focus on how to establish and run a business (70 hours)

### **Peer reviewed publications**

- 2018 Jónasdóttir, S. K., & Polgar, J. (2018). Scoping review: Services, systems and policies affecting mobility device users' community mobility. *Canadian Journal of Occupational Therapy*, 85(2), 106–116. doi:10.1177/0008417417733273

- 2018 Jónasdóttir, S.K., Hand, C., Misener, L. & Polgar, J. (2018): Applying case study methodology to occupational science research, *Journal of Occupational Science*, 25(3), 393-407. doi: 10.1080/14427591.2018.1480409
- 2018 Jónasdóttir, S. K., Egilson, S.Þ & Polgar, J. (2018): Services, systems, and policies affecting community mobility for people with mobility impairments in Northern Iceland: An occupational perspective, *Journal of Occupational Science*, 25(3), 309-321, DOI: 10.1080/14427591.2018.1474797

### Other publications

- 2008 Benediktsdóttir, H.A, Kristjánsdóttir, G. H. & Jónasdóttir, S.K. (2008, October 21). Hvaða hindrunum mætir fólk með mænuskaða? [What hindrances does people with spinal cord injury encounter?]. *Morgunblaðið*

### Conferences and other presentations

- 2017 Oral presentations:  
 Jónasdóttir, S.K., Egilson, S.T. & Polgar, J., *Systemic factors affecting community mobility for people with mobility impairments*, The Canadian Association of Occupational Therapists National Conference - OS stream, Prince Edward Island, Canada, June 21-24th, 2017.
- Jónasdóttir, S.K., Polgar, J. & Hand, C., *Case study methodology and the study of occupation*, The Occupational Science Europe conference, Hildesheim, Germany, September 8-9th, 2017

Jónasdóttir, S.K., Egilson, S.T. & Polgar, J., Áhrif þjónustu, stjórnsýslukerfa og stefnumótunar á möguleika fólks með hreyfihamlanir til að komast á milli staða [*Systemic factors affecting community mobility for people with mobility impairments*], University of Akureyri, Iceland, August, 2017

2015

Poster presentation:

Jónasdóttir, S. K., Egilson, S. T. & Polgar, J. *Services, systems and policies affecting community mobility for people with mobility limitations in northern Iceland*. Occupational Science Europe Conference, Bournemouth University, United Kingdom. September 3-4, 2015

2015

Poster display and one-minute presentation:

Jónasdóttir, S. K., Rudzicz, F. & Polgar, J. *An Online Assistive Technology Rating System for Caregivers*. Inaugural AGE-WELL NCE Conference. Calgary, AB. October 21-23, 2015

**Contributions as Peer Reviewer for Journal manuscripts**

2018 - present

Iðjuþjálfinn – Icelandic Occupational Therapy Journal